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Personal and Environmental Influences on the Long-term Caregiving Experiences of Individuals Living with an Adult Family Member with Severe Traumatic Brain Injury.

by

Heather Lynn Lissel ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements of the degree of Master of Science

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *Personal and Environmental Influences on the Long-term Caregiving Experiences of Individuals Living with an Adult Family Member with Severe Traumatic Brain Injury* submitted by Heather Lynn Lissel in partial fulfillment of the requirements for the degree of Master of Science in Medical Sciences – Public Health Sciences.

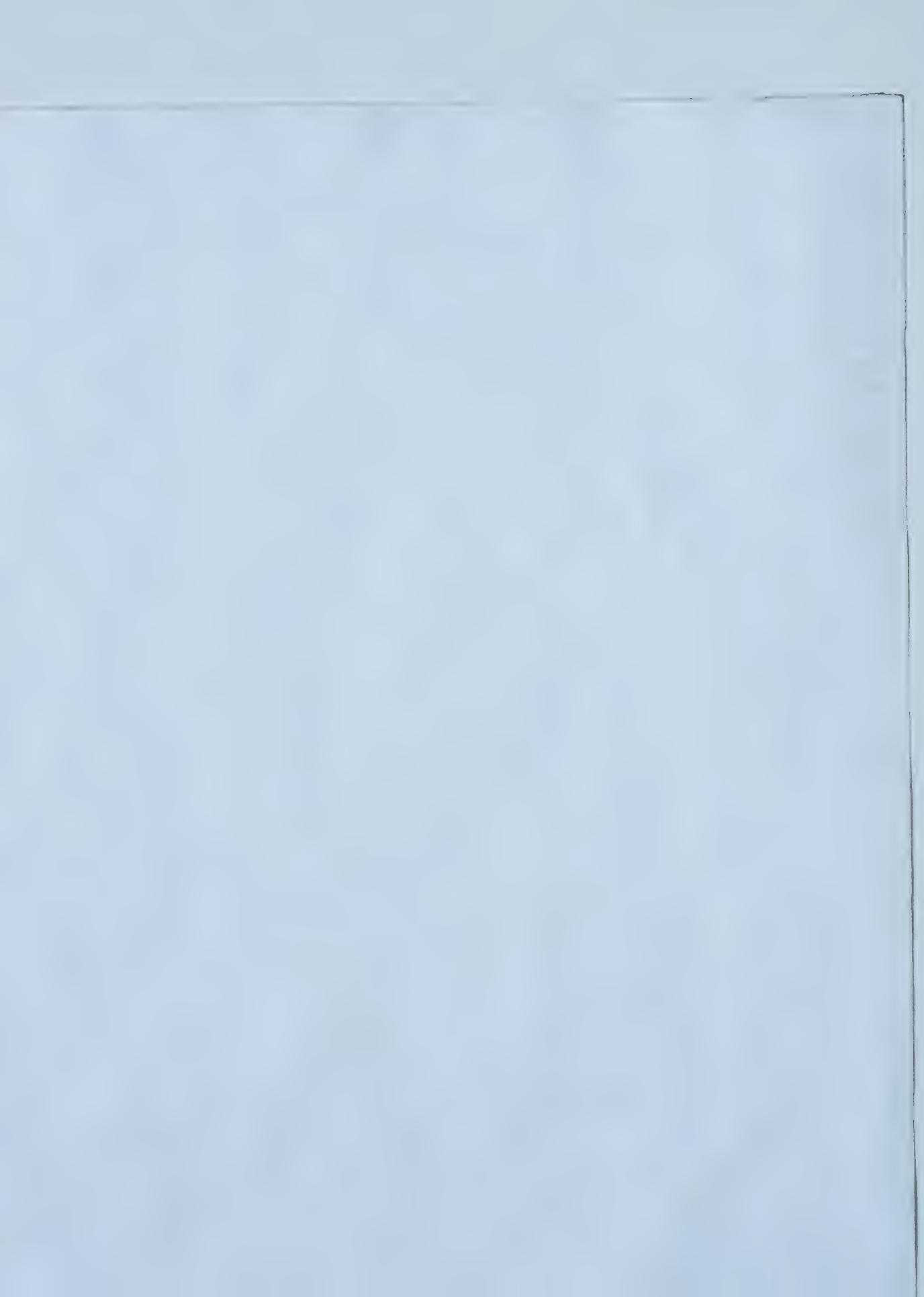This thesis is dedicated to my husband - you really know how to get a person motivated.

ABSTRACT

This study is a qualitative exploration of the caregiving experience, focusing on the interplay of personal and social influences that shape that experience.

Semi-structured interviews were conducted with nine individuals providing care and support to an adult family member with severe traumatic brain injury in the caregiver's home. Caregivers' experiences were characterised by two prominent transitions: Coming Home, and Rebuilding. Sub-themes within each reveal that, at least for some caregivers, major goals of caregiving are to assist in recovery, build the injury survivor's independence, and regain their own sense of an independent identity. Findings show that these goals are not well supported by society.

Recommendations focus on resolving the disjuncture between caregivers' goals and those reflected in social attitudes, institutional practices, and policy. A stronger emphasis on client input into goal-setting and long-term outcomes measurement that reflects client impact are proposed.

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Traumatic brain injury is common and can permanently affect the ability of individuals to function independently. Many individuals who have experienced a severe brain injury live in the community with the care and support of family members. Family caregivers are subject to tremendous stress and burden. In spite of this, many continue caregiving for many years. More can be learned about how to support caregivers and survivors by looking at the experiences of family caregivers who appear to have maintained their well-being while managing the caregiving role for a number of years. This study looks at the influence that caregivers' personal characteristics, and social/environmental factors have on the caregiving experience.

Epidemiology of traumatic brain injury

Traumatic brain injury – damage to living brain tissue caused by a blunt or penetrating external force (Vogenthaler, 1987) – is not a new phenomenon but is one that is rapidly gaining attention due to improved survival rates and increased advocacy by brain injury organizations. In Alberta, Canada, the location of this study, approximately 2500 individuals are admitted to hospital with varying degrees of brain injury each year (Alberta Centre for Injury Control and Research [ACICR], 2001b). About twenty per cent require treatment in a special care unit while in hospital, providing a general proxy of the severity of their injuries (ACICR, 2001b).

Canada-wide, the overall household prevalence of traumatic brain injury (TBI) has been estimated to be 62.3 per 100,000 adults 15 years of age and older (Moscato, Trevisan, and Willer, 1994). Eighty-four per cent had co-occurring disabilities and approximately half of these had more than two co-occurring disabilities (Moscato et al., 1994). The Brain Injury Association of the United States of America [BIAUSA] reports that 27% of individuals hospitalized as a result of TBI sustain moderate to severe brain injuries resulting in lifelong disabling conditions (BIAUSA, n.d.).

Young to middle aged adults comprise the largest proportion of head injury victims. In Alberta, Canada, almost half of all individuals hospitalized with a TBI are between the ages of 15 and 44 (ACICR, 2001a). The mean age of those hospitalized is

less than 35 years (ACICR, 1999). Males outnumber females nearly 2 to 1 (ACICR, 2001b). The leading cause of head injury hospitalizations in the province is falls, followed closely by motor vehicle collisions (ACICR, 2001b).

Data on the life expectancy of individuals with severe brain injury is not readily available, however it is reasonable to expect a normal life span, given the continuing improvements in technology and health care (Carson, 1993). Many will return to the community in the care of family members who assume primary responsibility for their long-term well-being (Jacobs, as cited in Carson; Brzuzy & Corrigan, 1996).

Outcomes

TBI is unique from other cognitive disorders in that functional outcomes are unpredictable and highly varied (Vogenthaler, 1987). The nature and severity of the injury and the location of the brain that is damaged will both influence the type of deficits an individual will experience. TBI is classified as either open (penetrating) or closed. Penetrating injuries occur when an object (such as a bullet) fractures the skull and penetrates the brain tissue, usually in a fairly localized area (Vogethaler, 1987). In these instances, it can usually be predicted that functions associated with the damaged area of the brain will be hindered.

A closed injury occurs when the skull collides with another object (such as a windshield). In this circumstance, injury tends to be more diffuse, as the brain 'rebounds' inside the skull, and tissue, nerves and blood vessels twist and tear. This type of injury results in a "mosaic of disabilities" (Vogenthaler, 1987) that are more generalized and difficult to predict. Motor vehicle collisions (the most common cause of TBI in this study) is most likely to result in diffuse injury to the brain.

TBI generally falls into four categories of severity: mild, moderate, severe, and catastrophic (Vogenthaler, 1987). It is now widely recognized that even mild brain injuries, in which the survivor may be treated in emergency and discharged, can have a major impact on ability to function in one's previous activities. Impaired memory, decreased concentration, fatigue, and irritability are a few of the symptoms which may cause prolonged difficulty for individuals who incur a mild brain injury (Vogenthaler,

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1987). Those with moderate brain injury typically experience a period of unconsciousness of one to 24 hours and may have more readily recognizable symptoms such as spasticity, seizures, and problems in language, memory and judgment. Individuals may require long periods of rehabilitation before being able to return to work and other pre-injury activities (Vogenthaler, 1987).

Severely brain injured individuals generally include those who have been in a coma for more than 24 hours and will have more serious deficits than those with moderate injuries (Vogenthaler, 1987). Overall, individuals who have sustained a severe brain injury may experience substantial deficits in their physical, cognitive, executive and psycho-social functioning. Physical problems which may be present include epilepsy, paralysis, speech deficits (an inability to form speech or understand speech), and limitations in sensory function (e.g., sight) due to damage in the controlling portions of the brain (Vogenthaler, 1987). Cognitive deficits include decreased alertness, lethargy, problems learning new information (though old information may be remembered), severe memory deficits, inability to plan or problem-solve and impaired perceptual functions such as spatial relations or attention to detail (Vogenthaler, 1987). Executive function refers to the ability of the brain to execute plans. Another feature of a deficit in executive function is that individuals are often not aware of their limitations, resulting in unrealistic goals and an inability to learn from past successes or failures (Vogenthaler, 1987). Psychosocial problems may be caused by direct damage to the portions of the brain that control these functions, or may arise as a result of the anxiety or depression that individuals experience as a result of their situation. Problems in this area include impulsive behaviour, poor judgment, emotional lability (rapid and dramatic mood swings), sexual disinhibition, and self-centredness (Vogenthaler, 1987). The majority of survivors in this study have incurred a severe brain injury.

Catastrophic brain injury is characterized by prolonged coma, followed by a persistent state of vegetation (Vogenthaler, 1987). Highly specialized care, usually in a long-term care facility is usually required.

Due to the traumatic nature of brain injury, it can also be accompanied by injuries to other body parts, such as limbs, spinal cord, and internal organs. If severe, these injuries can also impact long-term function.

Family impact

Thanks largely to studies of caregiver-related stress, it is now widely recognized that survivors' behavioural problems outweigh their physical disabilities in terms of the burden caused to caregivers. The impaired behavioural functions of the survivor can result in tremendous stress, fatigue, and frustration as family members struggle to deal with the survivor's constant demands for their time and attention, embarrassing behaviour in social situations, uncontrollable anger or violence, paranoia, struggles for control, and emotional dependency (Lezak, 1988). The need for constant vigilance to protect the survivor from harm (for example, if there is a tendency to wander) increases the burden on caregivers and other family members. Of course, not all survivors will present these problems and some may do so to a much lesser extent than others.

In addition, many survivors of severe traumatic brain injury will experience social isolation and loneliness leading to anxiety and depression (Morton and Wehman, 1995). Caregivers may feel helpless against these overwhelming emotional responses, and suffer their own erosion of self-esteem, guilt and feelings of inadequacy (Lezak, 1988). Without a proper understanding of brain injury, family members may initially respond by treating the survivor as they did prior to her/his injury, rather than recognizing that the changes are a permanent part of who that person now is (Lezak, 1986).

Lezak (1986) describes various reactionary stages that family members may go through when the survivor returns home. The stages are closely governed by their recovery expectations. Initially family members may expect a full recovery to normal. They will exhibit happiness and relief, which are gradually replaced by anxiety and discouragement as they perceive their expectations to be thwarted by the survivor's lack of motivation or their own inability to help. As expectations for a complete recovery continue to diminish, family members may begin to feel trapped in a situation they cannot deal with. Some may go through a period of mourning. Much later (after about 1½ to 2

years post-injury), family members may react to the permanence of the situation by reorganizing their lives so that they, as well as the survivor, can experience some degree of satisfaction and freedom.

Not all TBI survivors will remain dependent on family for the rest of their lives. As Jacobs, Blatnick, and Sandhorst (1990) state:

> For some people, lifelong living means returning to a full life or a close approximation of life as it existed before brain injury. For others, it means nearly total dependency on others for daily needs. For a large majority of those who experience TBI, it means something in between: being capable of meeting some personal needs, but needing various levels of assistance in other areas. (p. 2)

Systems of care

For many individuals living with severe brain injury, return to normal life is not an option, however some degree of recovery can be realized with appropriate rehabilitation. A combination of in-patient and community-based rehabilitation combined with long-term supports can enable many, even those with significant impairments, to live with, control and compensate for their challenges.[1]

In Alberta, in-patient rehabilitation for individuals with brain injury is provided at three centres, one in each of the province's major centres (Calgary and Edmonton) and one in central Alberta (Ponoka). A variety of out-patient clinics and social work services are provided through these and numerous other community-based programs. Rehabilitation, relearning and community re-integration is supported to varying degrees throughout the province by private and not-for-profit agencies. The system of treatment, rehabilitation and long-term community supports has been historically characterized by a lack of integration between the various organizations serving individuals with brain injury and their families (ACICR, 2000).

Individuals living with brain injury and their families have access to funding for user-pay services through the Workers' Compensation system, private litigation

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[1] For a powerful, first person account of living with brain injury, read Claudia Osborn's autobiography, titled Over my head: A doctor's own story of head injury from the inside looking out.

settlements and publicly administered financial support programs for the disabled. At the time of writing, individuals age 18 and older did not have access to public funds to support their specialized needs. Agencies and consumer groups have been actively advocating for several years for public funding to increase housing and treatment options and ensure an adequate range of community-based services to meet the needs of survivors and families over the long-term.

The Brain Injury Rehabilitation Program [BIRP] in Ponoka, Alberta, was a partner in this study, and falls within the mandate of the Alberta Mental Health Board. BIRP offers in-patient rehabilitation services to individuals aged 16 to 65 with non-progressive brain injury (primarily traumatic brain injury). A full complement of rehabilitative therapies is provided to improve residents' physical, cognitive, behavioral and emotional functioning, and help them attain success in social and community reintegration. Services are provided in the following areas: clinical dietetics, medical services / specialists; neuropsychology; nursing; occupational therapy; pastoral care; pharmacy; physical therapy; psychology; recreation therapy; special education; speech-language pathology; social work; and vocational rehabilitation (BIRP, n.d. -b).

Admission to the program is based on referral by self, family, friends, or medical professionals. Individuals will be accepted up to 3 years post-injury from anywhere in the province of Alberta. Given the nature of the Program, those accepted have typically sustained severe brain injuries.

Families are encouraged to be a part of the rehabilitation process. When it is determined that both patient and family are ready, regular weekend stays at home are incorporated into the rehabilitation program. No formal limits are placed on the length of stay. An assessment of the patient's progress and the appropriateness of community living arrangements is taken into consideration. Approximately 62% of all patients (all causes of injury) in the program are discharged to a home environment. Between 1991 and 1997 inclusive, 115 individuals with traumatic brain injury were discharged home (BIRP, 1998).

<u>Rationale</u>

The primary purpose of this study was to examine the ways that that caregivers' personal characteristics and the wider social environment influence their caregiving experiences over the long-term. A preliminary review of the literature on caregiving revealed that there is more to be learned about the role family caregivers play in the lives of adult brain injury survivors, and the factors contributing to their ability to sustain this role over a period of several years. The study was guided by the assumption that a variety of internal factors (e.g. caregivers' emotional, physical, and psychological characteristics) and external conditions (e.g. social, cultural, economic and geographic factors) influence the caregiving relationship.

Substantial contributions to the literature on stress and burden among family members of individuals with brain injury have raised interest in the unique experiences of this group of individuals. This body of research drew attention to the substantial burden that family members face and the need for additional services to alleviate that burden (Miller and Lawton, 1997). More recent research is now addressing the positive experiences that caregivers appear to derive from their role as a way of enhancing the ability to facilitate caregiver adaptation (Kramer, 1997b). This type of information is valuable for clinicians and practitioners seeking to improve identification, prevention, and treatment of caregiving-related pathologies, however, it is less appropriate for use in identifying the broader social factors that inhibit or enhance community re-integration and quality of life for both survivors and their families.

Noonan and Tennstedt (1997) noted that there may be value in studying the experiences of caregivers who appear to be doing well. They state:

> While it is sensible that future caregiver interventions and public policymaking focus on distressed or otherwise at-risk caregivers (Kane and Penrod, 1995), it is likely that these initiatives would benefit from the experiences and strategies of caregivers who have persevered. It would also seem a wise investment to explore ways of ensuring that these caregivers continue to survive, rather than take for granted their lasting involvement in this vital link of the long-term care system. (p. 793)

E. K. Abel (1990) has noted that many caregiver studies contain the unstated assumption that it is preferable to prolong family caregiving. A further assumption is that a lack of stress, or the existence of satisfaction, among caregivers will lead to this outcome. From a clinical perspective, research that describes the factors that contribute to caregiver well-being and burden is valuable, however it does not explore the impact that caregiver well-being has on survivor outcome.

Previous research suggests that the distancing of caregiver and survivor does not always signify an end to the caregiving relationship and may have a positive influence on caregiver well-being. In a study of marital breakdown following the injury of a spouse, Wood and Yurdakul (1997) found that separation seemed to provide relief from stress and that "some [spouse caregivers] openly stated that they wished to continue providing support so long as this did not mean cohabiting, because the relationship had ceased to be meaningful," (p. 499).

Studies addressing lifelong living and the long-term quality of life of adults who have sustained a TBI (Beals, Mathews, Elkins, & Jacobs, 1990; Jacobs et al., 1990) reveal important relationships between the social context and survivor living arrangements. Research that specifically examines the role of caregivers in supporting long-term living arrangements would be valuable.

On a more basic level, there is little published research that takes a systematic approach toward describing caregiver roles and experiences after they have been in the caregiving role for several years. Studies that describe caregiver experiences during the initial period of adjustment or during periods of stress, provide only a partial picture of the day to day life of caregivers as they manage their roles and responsibilities. A survey of 130 Albertans living in families with a brain injured child or adult suggests that caregivers' roles go beyond coping with stress and burden, to dealing proactively with the challenges they face and planning for the future (Howden, 1991).

The research questions

In this study, a caregiver is defined as a family member who is providing the majority of the care or emotional support needed by someone with a traumatic brain

injury. The caregiving arrangement of interest is that where the survivor was either living with the caregiver, or living independently (i.e., not in a long term care centre).

The questions this study seeks to answer are:

1) What personal characteristics of caregivers of adults with brain injury influence their ability to provide care over the long term?

2) What environmental factors influence the ability of caregivers of adults with brain injury to provide care over the long term?

3) What are the mechanisms by which personal and environmental factors interact to shape caregiving experiences?

Answers to these questions will help to advance our understanding of the roles and experiences of caregivers of adults with brain injury over the long term and provide information that will help to create more effective and appropriate policy and community-based programs to support individuals with brain injury and their informal caregivers.

The present study is a qualitative exploration of caregiving experiences, designed to answer questions about caregivers' abilities to provide long-term care in their own home to an adult family member who has sustained a severe brain injury. Most of what we currently know about being a relative and caregiver of an adult TBI survivor comes from three sources. One is from families themselves, in the form of biographies such as Courage after coma: A family's journey by M. Mathewson (1997). Another is the voluminous collection of clinical guides and texts, including resources designed to educate and assist family members (e.g., Brain injury: Coping with the results produced by the Glenrose Rehabilitation Hospital).

The third body of literature comprises published research on brain injury outcomes and the impact of TBI on caregivers and family members. The focus of the literature dealing with TBI caregiving is on providing new insights into the relationship between TBI and family or caregiver outcomes that are important for the design of more effective interventions to prevent caregiver morbidity and family breakdown. This chapter will review two dominant traditions in caregiving research, referred to here as the "caregiver stress/burden approach" and the "caregiver gains approach." Their strengths and limitations with respect to investigating the caregiving experience will be identified. A new research approach which combines principles of an ecological model of health with those of a strengths model of case management is proposed.

This chapter reviews and critiques only literature relevant only to informing the theoretical framework of this study. To avoid introducing bias into the interpretation of study findings, articles providing potential answers to the research questions were reviewed after the data were analysed (Patton, 1990). This information is introduced in Chapter 5: Discussion & Recommendations, where it is used to verify study results and address alternate explanations of the caregiving experience.

A critique of the caregiver stress/burden approach

The first studies investigating the plight of families impacted by brain injury emerged in the 1970s with the publication of seminal articles by Panting and Merry

(1972), Walker (1972), and Romano (1974; as cited in Perlesz, Kinsella, & Crowe, 1999). According to Perlesz et al. these studies were instrumental in alerting rehabilitation professionals to the wider impact of TBI on families.

In the 1980s, the work of the 'Glasgow team' of Brooks, McKinlay and others determined that there is a strong relationship between emotional and behavioural changes in the survivor and family burden, while the relationship between physical changes and burden is relatively weak (Brooks & McKinlay, 1983). Their research lead the way to a proliferation of empirical studies into the factors influencing relative and family stress. Like Brooks and McKinlay, these studies focused largely on the extent to which caregiver stress and family function were impacted by survivor characteristics such as injury severity, functional independence, and neurobehavioural problems (Kreutzer, Gervasio, & Camplair, 1994a; Sander, High, Hannay, & Sherer, 1997; Semlyen, Summers, & Barnes, 1998). Minimal attention was paid to the relationship between caregiver characteristics on stress and burden.

The work of Kreutzer et al. (1994a, 1994b), Semlyen et al. (1998), and Sander et al. (1997) greatly expanded and improved the tools and techniques available to identify caregivers at risk and devise more effective interventions based on an improved understanding of the stress process. All three teams of researchers used empirical methods to measure stress levels among caregiver populations and to identify multiple factors contributing to caregiver stress and family dysfunction. Their findings set a precedent for future studies by demonstrating that:

1. Caregiver stress (defined in terms of poor psychological outcomes such as depression and anxiety) is a serious problem not to be dismissed "as simply a passing 'grief reaction'" (Kreutzer et al., 1994b, p. 208).

2. Statistically valid and reliable measures can be used to successfully identify and quantify burden in relatives and caregivers (Serio, Kreutzer, & Witol, 1997).

3. Caregiver burden is a composite of "objective" stress factors — potentially verifiable and observable effects such as personal activity limitations

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(Reinhard, 1994) — and "subjective" factors such as caregiver perceptions (Semlyen, et al., 1998) and coping ability (Sander et al., 1997).

4. External factors such as relationship to survivor and time since injury may influence caregiver outcomes (Kreutzer et al., 1994a).

5. It should be possible to diminish the negative impact of TBI on caregivers and families via support groups (Kreutzer et al., 1994b), by encouraging more positive coping techniques (Sander et al., 1997), and reducing caregiver responsibility for survivor rehabilitation in the community (Semlyen et al., 1998).

These are important contributions that have greatly expanded our knowledge and understanding of the stressful dimensions of TBI caregiving. There are, however, several significant limitations associated with the continued focus on stress and burden and the use of empirical methods to explore the experiences and processes related to caregiving.

Perlesz, Kinsella, and Crowe (1999) are the only investigators to have compiled a critical review of the literature on the impact of TBI on the family, and they discuss many of these limitations. In their 1999 review of published research on the impact of TBI on the family, they observed that a majority of stress-focused researchers had overlooked evidence in their own studies that a substantial percentage of caregivers or family members were not reporting high degrees of stress. An example of this bias exists in Semlyen, Summers, and Barnes (1998) who report in their study that they found "high levels of distress ... [with] nearly half [italics added] scoring as cases" (p. 57). Apparently, then, more than half had not shown high levels of distress – a finding which Perlesz et al. would consider worthy of further investigation.

Perlesz et al. (1999), further point to biases in research which may contribute to artificially inflated estimates of the prevalence and severity of stress among caregivers. These include the type of measurement tools used, the time when stress is measured (e.g. immediately following return home, when stress can be expected to be high), bias in the types of questions asked (and, more importantly, those not asked) and sample bias produced by selecting study participants from support groups and counseling programs.

Through examining the findings of numerous stress/burden studies, they arrive at the following conclusion:

> The clear evidence of an absence of distress and burden in a significant proportion of family members after trauma warrants further investigation to determine factors contributing to family resilience and coping strengths following traumatic brain injury and to learn from these families' competence. (p. 26)

Like Perlesz et al. (1999), S. H. Zarit (1989) also identifies biases in the stress/burden approach which influence perception of the caregiving experience. Zarit questions the accuracy of self-reports of stress, asking whether those under stress can actually provide an objective view of their circumstances. Further, he points to the loss of important contextual information that characterizes caregiving outcomes. This occurs, he explains, when researchers' need to test sophisticated, multi-variate models requires them to disregard or control for important contextual variables such as the caregiver's relationship to the survivor and the survivor's residential status.

While stress/burden studies seldom examine the influence of environmental variables such residential status, length of time caregiving, and caregiver / care recipient relationship, researchers often refer to the social context to explain their findings. Hanneman and Blacher (1998) examined the predictors of parental attitudes toward institutional placement using indices and instruments to measure such things as placement intentions, home quality, family and child adjustment, and stress and coping. Interestingly, in their discussion, they identify the larger social context as a potentially significant factor influencing the intention to institutionalize. They state

> Political influences or the zeitgeist must surely affect parents' comfort in viewing placements and talking about them with friends, family members, and professionals. (p. 405)

Similarly Pearlin, Mullan, Semple, and Skaff (1990), address social variables in their development of the "stress process model" in caregiving. They state:

It is likely that because of the formidable barriers to suitable institutional care, however, many families continue to keep their relatives at home even after their resolve has been worn down. (p. 583)

Moreover, they define caregiving as a social act:

Looked at this way, caring and caregiving are intrinsic to any close relationship; that is, they are present in all relationships where people attempt to protect or enhance each others' well-being ... under some circumstances, however, caregiving is transformed from the ordinary exchange of assistance among people standing in close relationship to one another to an extraordinary and unequally distributed burden ... where impairment leads to increasing dependency on others for the satisfaction of basic needs, a profound restructuring of the established relationship can occur. (p. 583)

Because they are seldom the focus of investigation, social/environmental variables influencing caregiving are often only addressed in the discussion section of research articles. In their discussion of factors associated with caregiver distress, Semlyen et al. (1998), make the statement that "dependence in self-care and home-based tasks ... will affect the caregivers' quality of life and the amount of time they have for themselves" (p. 58) even though time and quality of life were not elements measured in their study. Wood and Yurdakul (1997) draw upon personal understandings of the marital relationship to explain how "physical and emotional distance created between the partners [caregiver and injured spouse] seemed [italics added] to relieve their sense of stress." (p. 499). Again, these statements are based on something other than research findings; a source is not stated.

Like Perlesz et al. (1999) and Zarit (1989), E. K. Abel (1990) also questions the soundness of removing variables from the social context in which they occur. Her primary criticism, however, is not that the practice results in biased findings but that it may result in the use of those findings to support unsound social policies. Her thesis is that, from a policy perspective, the outcome of interest should not be simply whether programs make caregivers "feel better" (p.144) but whether they actually improve their quality of life. In

contrast to the methodological criticisms of Perlesz et al., and Zarit, Abel's comments challenge the theoretical perspective underlying the bulk of caregiver stress/burden research. She states:

> The overriding issue is however, not how to relieve stress, but how to organize society to make care for the dependent population more just and humane. (p. 147)

Further, she warns that personalizing the causes of stress (i.e., limiting them to individual characteristics) may support or lead to policies aimed at helping caregivers adjust to their "unavoidable burdens" (p. 144) rather than addressing the root of those burdens which may well reside in the social, economic and political environment in which the caregivers live.

In summary, the tradition of stress-focused research has contributed to an improved but still greatly limited understanding of caregiver experience. As Abel (1990) points out, these limitations have the potential to greatly influence social policy, which in turn, will further determine the conditions caregivers face.

In response to the limited portrait of caregiving that stress/burden studies are able to provide, a new approach aimed at being a "corrective focus in caregiver research" (Miller and Lawton, 1997) has emerged in the general caregiving literature. This body of research investigates the positive aspects of caregiving, or "gains" which sustain caregivers. The contributions and weaknesses of this research direction are discussed next.

A critique of the caregiver gains approach

Caregiver gains research emerged as a response to the realization that not all caregivers experienced high degrees of stress and that many were able to identify positive attitudes toward their caregiving role. Researchers have since investigated the positive aspects, or gains, associated with caregiving, with a view to enhancing theories of caregiver adaptation (Kramer, 1997b) and enabling practitioners to utilize the client's own strengths and resources in overcoming obstacles (Tebb, 1995). This new approach has

opened up new levels of understanding of the caregiving experience, particularly with respect to caregiving processes.

A wide range of caregiving processes have been examined. Stephens, Norris, Kinney, Ritchie, and Grotz (1988) investigated caregivers' capacity to redefine events to derive inspiration or personal growth. In their desire to explain "why some caregivers fare better than others," Noonan and Tennstedt (1997, p. 785) examined meaning in caregiving as both a process and an end-state and found that the two bore different associations with key variables of psychological well-being. Smerglia and Deimling (1997) looked at care-related decision-making for caregivers of elderly family members and found that satisfaction with decision-making was a better predictor of caregiver health than the demands of care. The research of Wallhagen and Brod (1997) into perceived control and well-being in Parkinson's disease accentuated the interaction between caregiver and care recipient perceptions. Neufeld and Harrison (1995) examined whether reciprocity – the process of exchanging valued resources between individuals – existed in the carer's relationships with friends and family as well as with the care receiver, while Kramer's (1997a) research found relationships between differential processes of coping (e.g. emotion-focused vs. problem-focused) and variations in caregiver gain.

In a different vein, Szmukler, Burgess, Herrmann, Benson, Colusa, and Bloch (1996) developed and tested a new self-report measure of the experience of caring for a relative with a serious mental illness that included measures of positive personal experiences in caregiving (e.g., increased confidence, learning more about oneself) and positive appraisals of the caregiver's relationship with the care recipient (e.g., feeling that the care recipient makes a valuable contribution to the household, and enjoying her/his company).

Studies into caregiver gain have, to some extent, also contributed to an expansion of the theoretical perspectives within which the research questions are defined and the use of qualitative methods to explore those questions. In an article on the theoretical perspectives concerning caring for elderly persons with dementia, Farran (1997) explores the positive implications of adopting an existentialist approach to exploring the caregiving experience. Existentialism, as presented by Farran, provides the researcher with certain

assumptions about human experience which can then be applied to the caregiving experience, for example the belief that human experience is characterized by tension between freedom of choice and the need to assume responsibility. She suggests that

> Combining what we know from a stress/coping paradigm and what we might learn by incorporating existential perspectives suggests that we may be able to use more extensive research designs and methods to more fully answer the following questions ... How do prior values influence the decision to provide care to an impaired family member, and [what] are the process and outcomes associated with this experience? ... How is it that family caregivers 'make sense' of these experiences and do so well under difficult circumstances? (p. 255)

Farran's (1997) proposal to apply alternative theoretical perspectives to the understanding of caregiving addresses a limitation in other caregiver gains studies. In a critical review of 29 studies published on the subject of caregiver gain among informal caregivers of older adults, Kramer (1997b) points to the lack of theory and conceptual clarity underlying a majority of research studies. This, in combination with methodological problems such as an over-reliance on quantitative methods, contribute, in Kramer's view, to "limited cumulative knowledge" (p.231) on the subject of caregiver gain. She recommends the adoption of a standard conceptual model "generated through the integration of several different theoretical perspectives" (p.229), for example, a blend of stress/process theory, existentialism, and social exchange theory, that can be tested and further developed. Abel (1990) reiterates the recommendation that alternative theoretical insights be used to examine questions about the caregiving experience.

Where caregiver gain literature expands the possibilities for understanding caregiving, most studies remain committed to the goal of enabling caregivers to better cope with their situation. Neither the stress/burden approach nor the caregiving gains approach question that families have a responsibility to provide care, and many seem to make the implicit assumption that family caregiving is preferable, even though, as Willer, Flaherty, and Coallier (1999) remark, "there is little concrete evidence that individuals with brain injury have improved outcomes as a result of family interventions" (p.12). The

impact of this limitation is that important questions such as 'what impact can / do family caregivers have on survivor outcomes?' remain unanswered. Without answers to such questions, solutions to the issues facing caregivers remain locked in an individualized treatment model that seeks to alter their or their family's responses in order to avoid morbidity and dysfunction.

The next section presents a case for a theoretical framework that addresses these limitations by blending the perspectives of ecological health promotion with those of a strengths-based approach to case management. Key sources are presented and discussed in order to identify the strengths and potential weaknesses of this approach.

Theoretical framework: A strengths-based ecological model of caregiving

"Strengths-based ecological model of caregiving" is a term that will be used in this report to describe a new approach to investigating phenomena related to the caregiving experience. The motive for adopting a new approach comes from the limitations of the stress/burden and caregiver gains literature and the recommendations of their reviewers and critics presented above. The approach is derived from the blending of two perspectives – one theoretical and one practice-based – that seem to best address those shortcomings. Although ecological health promotion and strengths-based case management are not historically linked, they are conceptually similar, in that they both perceive of the individual as an active agent in her/his environment, with the power to control the environmental determinants that impact upon health, well-being and the achievement of personal goals.

Green, Richard, and Potvin (1996) provide a well-rounded discussion of the evolution of the ecological foundations of health promotion. Ecological perspectives first emerged in the field of public health with the concept of health as an interaction between humans and their environment. More recently the influences of the ecological approach can been seen in the Ottawa Charter and the Epp Framework for Health Promotion. A central canon in the ecological model of health promotion is that of healthy, supportive environments. Green et al. explain:

The ecological model of health promotion presents health as a product of the interdependence between the individual and subsystems of the ecosystem (e.g. family, community, culture, physical and social environment). To promote health, this ecosystem must offer economic and social conditions conducive to health and healthful lifestyles. These environments must also provide information and life skills, so that individuals can make decisions to engage in behavior that maintains their health ... Finally, healthful options among goods and services offered must be available. In the ecological model of health promotion, all these aspects are envisioned as determinants of health. They also provide essential support in helping individuals modify their behaviors and reduce their exposure to risk factors. (pp. 271-272)

Ecological principles can also be recognized in recent revisions to the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2) by the World Health Organization. The ICIDH-2 is based on a "social model of human functioning and disablement" (World Health Organization [WHO], n.d. - b, p. 2) and considers factors such as social attitudes, institutions and laws, in a "Contextual Factors Classification" which identifies both personal and environmental barriers to full participation. Three levels of disablement are recognized within the ICIDH-2. These are: impairment ("a loss or abnormality of body structure or of a physiological or psychological function"); activity limitations (limitations in "the nature and extent of functioning at the level of the person"); and retrictions in participation ("the nature and extent of a person's involvement in life situations in relation to Impairment, Activities, Health Conditions and Contextual Factors") (WHO, n.d.- a, p. 2).

The WHO model links the three concepts of impairment, activity and participation causally in a linear fashion (Heinemann and Whiteneck, 1995). Examples of the three would be: loss of limb or loss of vision (impairments); limitations in ability to take care of oneself or maintain a job (activities); and restrictions in one's ability to participate in community activities, obtain a driving license, etc. (participation) (WHO, n.d. - a, p. 2)

In an ecological model, the environment is seen as "a factor that predisposes, enables, and reinforces individual and collective behavior" (Green et al., 1996, p. 272). Change is effected through action at the individual and environmental level (e.g., family, community, policy). Effectiveness of interventions depends upon their fit with the individual, the nature of her/ his problem, and the environment in which the solution is to be applied. Empowerment plays a key role in enabling individuals to "control the determinants of their health" (p. 279).

A slightly different notion of change from an ecological perspective is offered by Cowen (1991) who, speaking about the pursuit of psychological wellness, says:

A full consideration of the topic of psychological wellness requires that attention be directed to key sources of influence that advance or restrict such an outcome, that is, the life circumstances and family milieu in which a child develops, the effectiveness of a child's total educational experience including both home and school inputs, the molding impact of significant social settings and systems in which the person interacts, and the extent to which a larger society and its mediating structures are just, empowering, and offer hope. (p. 406)

Following from this, he explains that "the comprehensive pursuit of wellness will ultimately require a range of divergent but conceptually yoked solutions" (p. 406). These include actions to strengthen individual qualities of competence and resiliency, and modify social systems to ensure that key institutions such as school and work actively contribute to healthy outcomes, and that the policies and social conditions under which people live enable and empower them to use their competencies to pursue enhanced wellness.

The necessary interplay between individual and environment is a central concern in the practice of a strengths-based approach to case management. Case management is a term that takes on different meanings depending on the setting in which it is used (Smith, 1998). Most definitions, however, encompass some form of external facilitation of clients' progress toward positive goals within certain parameters. The points of variation may be around establishing goals (e.g. more or less client-directed), choosing the mode of facilitation (e.g. individual or team approach), the extent of support provided (e.g. short-

term vs. long-term), and the parameters within which assistance is provided (e.g. more or fewer cost-related constraints). The strengths perspective is one of the more recent case management approaches to be developed, and focuses on providing support over the long-term to enable clients to utilize their personal strengths and harness community resources to achieve self-identified goals.

The strengths model, also known as the developmental-acquisition model, was developed in Kansas in the early 1980s and has been used extensively in the area of mental health (Saleeby, 1996) to optimize individuals' functioning in a non-institutional community setting. The strengths model, as defined by one of its key developers, C.A. Rapp, is "a model of case management in which the focus is on identifying and enriching client strengths and securing the resources needed by the client to integrate into the community with the express purpose of improving the quality of his or her life" (as cited in Standard, 1999, p. 170). Evaluation of the model has shown positive results for consumers in terms of increased community tenure, high levels of individual goal attainment, improved vocational and independent living status, high levels of consumer satisfaction, and improved quality of life (Kisthardt & Rapp, 1992; Standard, 1999).

The strengths-based approach represents a reaction to the dominance of "psychosocial approaches based on individual, family, abnormality, victimization and disorder" (Saleeby, 1996, p. 296) In contrast to the "pathology" model (p. 298), the strengths model adopts an approach where therapy is possibility focused rather than problem focused, goals are defined by the aspirations of the client rather than the practitioner, the key tools to reach goals are the clients' strengths and capacities rather than the professional's skills and knowledge, and the desired outcome is membership in the community as opposed to the reduction of negative symptoms (Saleeby, 1996).

A common criticism of the strengths based approach to case management is that it downplays or discounts the reality of a client's problems (Saleeby, 1996). While much less emphasis is placed on the limitations imposed by chronic illness or disability than in a pathology model, diagnosis and assessment of client problems is still an important part of social work practice in the strengths based model. To avoid the possibility of the diagnosis becoming a "cornerstone" of the client's identity, however, case managers are

tasked with the responsibility of assessing client strengths – namely those resources that have enabled them to survive so far (Saleeby, 1996). The client / case manager relationship is primary and is characterized by professionalism (Rapp & Wintersteen, 1989) and active, continuous collaboration (Berg-Weger & Tebb, 1998; Kisthardt & Rapp, 1992). Advocacy to obtain needed services and supports becomes an important case management function (Kisthardt & Rapp, 1992).

Saleeby (1996) maintains that the strengths perspective is not a theory, but represents an "emerging body of principle and method ... [that] create[s] opportunities for professional knowing and doing that go beyond the boundaries of the 'technical-rational' approach so common today" (p. 303). The strengths perspective has been integrated into social work practice in a number of domains including work with individuals living with chronic illnesses and mental disability. The emergence of the strengths-based approach into work with caregivers has been facilitated by Susan Tebb of the St. Louis University School of Social Service. The Caregiver Well-Being Scale developed by Tebb (1995), integrates the concepts of caregiver well-being and empowerment in a tool that has since been used to carry out client assessment, assist in individual and group interventions, track client outcomes, and evaluate programs (Rubio, Berg-Weger, & Tebb, 1999). This study utilized the Caregiver Well-Being Scale to assess the well-being of caregivers of adults with brain injury and identify those who appeared to be doing well. Additional information about the scale and its use in this study are provided in the next chapter.

Summary

This study asks questions about the personal and environmental factors that interact to define the caregiving experience. Previous research has greatly expanded our understanding of variables and processes involved in caregiving, however they provide only a partial view of the full caregiving experience. These shortcomings are the result of researcher bias, weak conceptualization of key caregiving variables, and methodological limitations. Without adopting new study approaches, the implications for research are: continued growth in the number of caregiving studies producing results that cannot easily be compared due to differences in key variables such as time (Semlyen et al., 1998);

limited cumulative knowledge resulting from a "lack of conceptual clarity, methodological problems, and the wide variability in the foci of the studies" (Kramer, 1997b, p. 231); and reliance on outcome measures that don't reflect the "real-life" problems faced by caregivers (Semlyen et al., 1998, p. 54).

In turn, these short-comings limit the ability of decision-makers in both the administrative and political realms to conduct the kind of critical review that is required to make sound policy judgments. Zarit (1989) notes the importance of providing evaluative information on the effectiveness of interventions to both service providers and funders. Abel (1990) points out that studies focused only on the application of findings in the clinical setting could be used to support policies that further disadvantage an already vulnerable population. Additionally, significant questions around who is responsible for ensuring caregivers' needs are met (Willer et al., 1999) are not a consideration in previous stress/burden and gain literature. Without broaching these important issues via a theoretical perspective that considers health as a product of both the individual and the environment it will be difficult to achieve Cowen's aspirations of "a range of divergent but conceptually yoked solutions" (1991, p.406) to the problems that impact on caregiver well-being.

This literature review suggests that valuable knowledge about the phenomenon of caregiving can be gained by adopting new ways to pursue the research question (Marshall & Rossman, 1995). These questions are: what personal characteristics of caregivers of adults with brain injury influence their ability to provide care over the long term; what environmental factors influence the ability of caregivers of adults with brain injury to provide care over the long term; and what are the mechanisms by which personal and environmental factors interact to shape caregiving experiences? This study places these questions within a new framework and adopts a qualitative methodology to explore them. Findings will reveal new insights into the caregiving experience that may be used to direct further research, policy and practice.

The merits of a phenomenological orientation

This study is a qualitative investigation into how personal and environmental factors interact to shape caregiving experiences. The methods and approach have been influenced by, but do not strictly adhere to, the phenomenological research approach, thus the phrase "phenomenological orientation" will be used. A phenomenological orientation is used in this study because it allows the researcher to explore the thoughts and actions of those who are experiencing the phenomenon under investigation (Morse & Field, 1995). A review of the phenomenological tradition in sociology, such as that provided by J. Wilson (1983), reveals several tenets that lend support to the application of this perspective in the present study.

According to phenomenological sociologists, "the social world must be treated as the product of human thought and activity" (Wilson, 1983, p. 145). Roughly speaking this means that phenomenological inquiry focuses on reality according the subject, and not according to the preconceptions of the researcher. Phenomenology leaves open the door for subjects to disagree with what a researcher believes is important in defining and explaining a phenomenon of interest. This perspective is important to addressing a key limitation in previous caregiver research which downplays the positive aspects of the caregiving experience and/or makes assumptions about the kinds of stresses that caregivers may find burdensome.

Another important foundation of the phenomenological tradition is an emphasis on context. Quoting Schutz (1962), Wilson (1983) writes, " 'The first task of the methodology of the social sciences' ... should be 'the exploration of the general principles according to which man in daily life organizes his experiences, and especially those of the social world' " (p. 148). This emphasis fulfills an important need for contextual information in the current literature on caregiving. The focus on "exploration" gives respondents the freedom to describe their experiences within a context that is real to them, without being restricted by any pre-conceived notions the researcher may hold.

Finally, phenomenology recognizes the blurring of objective and subjective reality (Wilson, 1983) and the impossibility of separating the influence of what exists in reality and people's subjective interpretation of it. This is a very different approach than that taken by empirically-based researchers who grapple with the problem of separating objective and subjective factors related to stress and well-being.

Qualitative methods are a natural fit with phenomenological enquiry which rejects the structured data collection methods characteristic of quantitative research (Wilson, 1983). Phenomenology regards these methods, exemplified by scales and forced-answer questions, as giving a false image of objectivity. Instead, phenomenology is aimed at providing "accounts" of the phenomenon that, as much as possible, preserve the transparency of the informant's thoughts and beliefs to "enable someone else to understand what is going on" (Wilson, 1983, p. 162). Findings are reported with the intention of leaving conclusions open to varied interpretations (Morse & Field, 1995).

A phenomenological orientation is especially useful in this study as it enables the information to be used by a varied audience. Caregivers reading this report may find a new way to make sense of their experiences and truly appreciate their valuable role. For practitioners and decision-makers, the report may provide valuable information for informing policies or programs. In this study, the researcher's expectation is that different groups of readers will form different opinions about the data and that the findings will challenge all readers to find new ways of perceiving caregivers' role in the rehabilitation process.

Study methods

Previous research suggests that individuals who appear to be faring well in their caregiving role have not been extensively studied and would be a rich source of information about the caregiving experience over time (Farran, 1997; Noonan & Tennstadt, 1997; Perlesz, Kinsella & Crowe, 1999). Based on this information, the intent of the study was to conduct face-to-face interviews with a sample of caregivers who had been providing care over a period of several years and who were experiencing relatively high levels of well-being.

In order to identify such a group, the researcher employed purposeful sampling, via a telephone survey, in which key questions were asked about caregiver well-being. Purposeful sampling is defined by Patton (1990) as the selection of *"information-rich cases* for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research" (p. 169). Various means including previous research studies (Patton, 1990), may offer insight into which population "offer[s] the closest correspondence to the construct of interest" (Cook et al., 1985; as cited in Patton, p. 178).

The sample for the telephone survey was drawn by staff hired by the Brain Injury Rehabilitation Program in Ponoka, Alberta who had access to the patient database. The sampling began by selecting the names of survivors of traumatic brain injury (as opposed to other acquired forms of brain injury) who had been discharged between 1991 and December 21, 1998. A second criteria was that their file must show that the survivor was discharged home or to another independent living situation. This eliminated individuals discharged to long-term care, where it was assumed that the majority of their care would be provided by paid caregivers.

This process yielded the names of 114 survivors. These individuals, or their legal guardian where one was indicated, were contacted by letter and then by telephone to obtain permission to access patient information and to identify and obtain permission to contact the person's main caregiver. A caregiver was defined as the person who provides the most support to the survivor by helping her/him with housekeeping, personal care, rehabilitation or emotional support. This person may be a family member, friend, or relative, and they must not be paid for providing this support.

Throughout the process, individuals who had moved into a long-term care setting, or who indicated that they had no caregiver were eliminated from the sample.

The final sample was small – only 36 potential caregiver respondents. The primary reasons for attrition were inability to contact the legal guardian or survivor (38.6%, n=44) and ineligibility according to the three study criteria outlined above (21.1%, n=24). The 24 'ineligible' cases included some who had been admitted to long term care or depended primarily on paid care, and 18 cases (75%) where the survivor indicated that there was no

unpaid caregiver. The research assistant noted that several instances arose where survivors insisted they had no unpaid caregiver, even when she was aware through other sources that the individual was quite dependent on family. This problem may have been avoided by simply choosing to do the survey with a spouse or parent, or revising the definition of caregiver to mention 'such as parents or a spouse,' however the researcher decided against this. As such, the final sample of 36 potential caregiver respondents represents a convenience sample, consisting of individuals either self-identified or identified by a survivor or legal guardian as a primary caregiver. Characteristics of this sample are summarized in Table 3-1.

Table 3-1   Sampling statistics, telephone interview

Total, original database	114		**(100%)**
No letter sent	- 14		
- deported / moved out of country		-3	
- no address available		-8	
- deceased		-3	
Letters sent	100		
Letters returned	-16		
Phone calls made	84		
No answer / not in service	-13		
Phone number withheld	-1		
Telephone contact made	70	**(100%)**	**(61.4%)**
N/A, LTC or paid care only	-24	(34.3%)	(21.1%)
Refusal	-6	(8.6%)	
No English spoken in household	-1	(1.4%)	
Unknown	-3	(4.3%)	
Total eligible	**36**	**(51.4%)**	**(31.6%)**

A total of 28 caregivers completed the telephone survey. At that time it was found that an additional 3 caregivers were not eligible, either because they did not consider themselves to be a caregiver, or because they clearly were not, according to the study inclusion and exclusion criteria. Three others were ineligible because the survivor had been living for more than three months in a long term care facility. Two could not be reached. Table 3-2 outlines the final disposition of the calls.

Table 3-2 Disposition of calls for telephone survey

Eligible numbers	36
No answer or not in service	-2
N/A[a]	-6
Completed interviews	28

[a]contact was a paid caregiver (n=1); survivor said he was his own caregiver (n=1); contact was the legal guardian but didn't consider him/herself to be a caregiver (n=1); survivor now living in long-term care (n=3)

Sample selection: Face-to-face interviews

The design of the telephone survey was based on a mail-out questionnaire developed by researchers and administered to caregivers in a rural health region in Alberta, Canada (Deis, Simpson, and Jumaga, 1997). Questions were asked about the types and amount of care given, services and supports accessed by the survivor and by the caregiver, activities which were a support to the caregiver, and caregiver well-being. A limited amount of demographic information (e.g., age, education) was also collected for both the survivor and caregiver. Detailed information on the survivor's age at injury, and level of disability at discharge were obtained from patient files. The survey included four open-ended questions asking caregivers whether they felt caregiving had become easier in some ways and how, whether it had become more difficult and how, what caregivers felt their strengths were, and what would make their job easier.

The sample for the face-to-face interviews consisted of nine caregivers who had completed the telephone survey and who, based on the survey results, represented a reasonable cross-section of those individuals who, according to key questions in the survey, appeared to be faring well in their caregiving role.

To enable the researchers to identify those caregivers who appeared to be faring well in their role, respondents were asked to complete the Caregiver Well-Being Scale [CGWBS] (Tebb, 1995). The CGWBS is a validated instrument consisting of 45 items that measure two broad dimensions of caregiver well-being: satisfaction of basic needs (22 items); and satisfaction of the activities of living (23 items; Rubio, Berg-Weger, & Tebb, 1999). Each of the 45 questions is scored on a 5-point Likert scale where 1 indicates that the need is never or almost never met, and 5 means it is almost always met in a timely way. The scale was originally designed as a tool to assist case managers in working with clients caring for elderly family members to identify their strengths. The tool had previously been administered, in part, in a mail-out questionnaire in a rural region of Alberta (Deis, et al., 1997). Given its success in these contexts, and after review by other experienced researchers, it was determined that the scale could be successfully administered over the telephone and would yield valid information about caregivers' state of well-being.

Results of the CGWBS were compared with the overall tone of the survey, with information indicating the respondent's perception of her/his situation, and with respondents' answers to other questions that also indicated well-being. Overall, responses to the scale were consistent with other findings, lending support to the validity of the scale in this context.

CGWBS scores were one of three variables analysed to determine the final nine potential interview participants. The other two were the survivor's level of independence (as measured by a list of seven independence-related activities) and the amount of help the caregiver provided (as measured by a list of 11 caregiving-related activities). Relationship, income level, length of time in the caregiving situation and quality of the interview were also taken into consideration.

Because each of the 45 items in the CGWBS are positively worded and scored uni-directionally, it was possible to sum the scores to derive a rough measure of caregiver well-being. These measures were used to obtain a median score. Those scoring at or above the median were considered possible participants for the face-to-face interviews (n=15).

Through analysis of survey findings, it was discovered that well-being was positively related to survivor independence, therefore it was not acceptable to select only those individuals who scored highest on the CGWBS. For this reason, respondents were further ranked according to summed scores for the question on survivor independence and on level of care provided. Based on these scores, survivors were identified as either independent, moderately independent, or dependent. These categories were purely for the purposes of comparison and had no real meaning outside of the sample selection exercise.

Three potential respondents were selected from each category of survivor independence, with alternates available. All nine individuals were contacted by the researcher and agreed to participate in the personal interview. Due to external circumstances, several months had passed between the time of the telephone survey and the personal interviews. During this time three of the nine caregivers had stopped providing care in their own home. In all cases, the survivor had moved into an independent or semi-independent living arrangement, however caregivers were still heavily involved in providing care and/or support. It was decided to include them in the study as their experiences might provide valuable insight into the natural progression of long-term caregiving arrangements.

Sample characteristics

Table 3-3 presents the sample characteristics for the face-to-face interview alongside those of the telephone survey. Doing this highlights some important differences between the two samples which should be considered when reviewing the findings. Measures of disability included the total Rappaport Disability Rating Scale (RDRS), the Glasgow Outcome Scale, and the Ranchos Los Amigos Scale, recorded by the BIRP upon discharge (BIRP, n.d. -a).

Table 3-4 further compares the characteristics of survivors and caregivers according to whether the CGWBS scores were below the median for the group or at / above the median.

Table 3-3 Sample characteristics: Telephone survey and face-to-face interviews

Caregiver characteristics		Telephone survey (n=28)	Face-to-face interviews (n=9)
gender:	male	5 (17.9%)	1 (11.1%)
	female (%)	23 (82.1%)	8 (88.9%)
relation to S:	parent	17 (60.7%)	6 (66.6%)
	spouse	8 (28.6%)	2 (22.2%)
	other	3 (10.7%)	1 (11.1%)
marital status:	married	24 (85.7%)	8 (88.8%)
	other	4 (14.3%)	1 (11.1%)
age(years):	35 - 44	3 (10.7%)	1 (11.1%)
	45 - 54	9 (32.1%)	4 (44.4%)
	55 - 64	12 (42.9%)	4 (44.4%)
	65 - 74	4 (14.3%)	0 (0.0%)
income:	< $20,000 /yr	7 (26.9%)	1 (11.1%)
	$20,000 - 40,000 /yr	9 (34.9%)	3 (33.3%)
	> $40,000 /yr	10 (38.5%)	4 (44.4%)
	refusal		1 (11.1%)
employment:	empl. full-time	10 (35.7%)	3 (33.3%)
	empl. part-time	5 (17.9%)	1 (11.1%)
	not empl. / retired	13 (46.4%)	5 (55.5%)
care rel'ship:	living with S	20 (71.4%)	8 (88.8%)
	S on own	8 (28.6%)[a]	1 (11.1%)

Table 3-3, continued

Survivor characteristics	Telephone survey (n=28)	Face-to-face interviews (n=9)
male: female ratio	1.8:1	2:1
Ave. age at time of study	40.1 *(22 - 72)*	36.8 *(22 - 68)*
Ave. injury age (as of Jan /99)	32.5 *(16 - 69)*	31.2 *(17 - 63)*
Ave. years injured	7.9 *(3 - 19)*	5.6 *(3 - 9)*
Ave. years since discharge	4.4 *(1 - 7)*	4.0 *(2 - 7)*
Total RDRS	6.35	5.78
Glasgow Outcomes Scale	2.65	2.56
Ranchos Los Amigos	7.0	7.1

Note. A score of 4-6 on the total Rappaport Disability Scale indicates "moderate disability." The Glasgow Outcome Scale classifies scores between 2 and 3 as "moderately disabled," that is "able to look after oneself independently, however some previous activities (as work or in social life) are no longer possible due to physical or mental deficit." A score of 7 on the Ranchos Los Amigos Scale of Cognitive Functioning indicates "automatic, appropriate" behaviour, displayed as the ability to perform in familiar settings but with decreased judgment and problem-solving abilities, and the need for supervision for safety reasons. (BIRP, n.d. -b)

[a] includes one survivor who moved to a group home less than three months earlier

Table 3-4: Survivor characteristics for caregiver well-being categories

	Caregiver Well-being Scale Scores	
Survivor characteristics	at / above median (n=15)	below median (n= 13)
Average age	39.0 years	41.4 years
Average injury age	33.3 years	31.5 years
Average years injured	5.6	10.4
Average years since discharge	4.2	4.8

Barring the ability to calculate statistical significance, these data show that on the whole, the typical caregiver in both the telephone and the face-to-face interviews was a female parent between the ages of 55 and 64, living in a marital relationship and no longer working for pay. Most were living with the survivor who was most likely to be a male in his late thirties, injured for about six to eight years, and living with a moderate level of disability. Proportions indicate that interview participants may be slightly more likely to fall into the higher income brackets, and be less likely to be employed. Scores for the RDRS, the Glasgow Outcome Scale and the Ranchos Los Amigos Scale of Cognitive Functioning suggest a slightly higher level of functioning among survivors associated with the face-to-face interviews, however the categories within each scale are not discrete enough to make this claim.

Table 3-4 indicates that those caregivers displaying higher levels of well-being tended to be caring for younger family members, injured far more recently (as indicated by years since injury). This finding suggests that caregiver well-being may be linked in some way to the passage of time: either the length of time caregiving, or the time (i.e., year) in which the person was injured. In any event, it should be noted that the sample going into the face-to-face interviews, while internally heterogeneous, may unintentionally over-represent a certain segment of the caregiver population.

It should also be noted that the average years since discharge was much lower than was hoped (about four years). This may be due to difficulties in tracking individuals over longer periods of time, or an increased likelihood for survivors to move into long-term care after a certain period of time.

The interview process

Semistructured, face-to-face interviews were conducted with all nine caregivers over a three month period. The length of the interviews ranged from 45 to 90 minutes. Eight of the nine were completed in the caregivers' home and one was completed at the interviewer's office. In one interview, the caregiver's spouse - considered a co-caregiver by the respondent - was also present. He was encouraged to respond to the questions independently after his wife had had an opportunity to reply.

A semistructured interview format consists of "open ended questions that define the area to be explored, at least initially and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail" (Britten, 1996, p. 29). It is a useful approach to use when the researcher knows generally what aspects of a phenomenon s/he wishes to explore, but lacks the knowledge to form specific questions (Morse & Field, 1995).

The literature review, input from other knowledgeable researchers, and key findings from the telephone survey helped the investigator structure a set of guiding questions for the interviews.[2] The investigator first asked respondents to talk about how they became caregivers, then to talk about the best thing that had happened to them since they became a caregiver and why they felt that was the best thing that happened. They were also asked to describe their most difficult challenge during that time period and explain how it was challenging and how they got past it. The final question asked them for their advice to others, especially 'beginning' caregivers.

Interviews were taped and then transcribed by a professional transcriber. In one instance, the tape recorder failed and text was reconstructed from the investigator's notes. All transcripts were verified by the interviewer against the original tape recording. This task constituted an initial stage of data analysis, as it immersed the researcher thoroughly in the data, offered the chance to test early assumptions and look for possible themes within and between interviews.

In summary, the research questions this study seeks to answer are:

1) What personal characteristics of caregivers of adults with brain injury influence their ability to provide care over the long term;

2) What environmental factors influence the ability of caregivers of adults with brain injury to provide care over the long term; and

3) What are the mechanisms by which personal and environmental factors interact to shape caregiving experiences?

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[2]For a summary of key findings from the telephone survey, see Appendix E.

The questions devised for the face-to-face interview approach these questions in a broad fashion by eliciting information from the respondents regarding their perception of the caregiving role, what the most significant aspects of the caregiving experience are to them, and what kinds of things (e.g. events, actions, thoughts) sustain them during even the most trying times. The search for elements of personal and external factors and interactions between them, would guide analysis of the findings.

Data analysis and interpretation

"Data analysis is the process of bringing order, structure, and meaning to the mass of collected data" with qualitative data analysis being "a search for general statements about relationships among categories of data" (Marshall & Rossman, 1995, p. 111). As the questions in the present study were primarily a guide, analysis by question was not appropriate. A process of thematic analysis, "the search for and identification of common threads that extend throughout an entire interview or set of interviews" (Morse & Field, 1995, p. 139) was applied. This approach challenged the researcher to explore and extract the common essence of the caregiving experience from among the respondents' varied situations. As Morse and Field explain,

> Often the theme does not immediately 'jump out' of the interview but may be more apparent if the researcher steps back and considers, 'What are these folks trying to tell me?' The theme may be beneath the surface of the interviews but, once identified appears obvious. Frequently, these themes are concepts indicated by the data rather than concrete entities directly described by the participants. (p. 139)

In this study, thematic analysis brought order and structure to the mass of data depicting the varied experiences of caregivers.

Sense was made of the data via two cognitive processes, described by Morse and Field (1995) as "comprehending" and "synthesizing." Comprehending is the process of coming to an understanding of what is happening. In this study, two facets of comprehending emerged: the first was understanding why caregivers were providing care at home (What did that arrangement look like? How did it come about? Was it satisfactory to the caregiver?); the second was an understanding of how caregivers

managed to provide care in their home over the long term (What were their expectations? What role did they play in fulfilling those expectations? What strengths enabled them to succeed?). Comprehension was achieved through the development of several thematic groupings of the data. Transcripts were reviewed and portions of each transposed onto index cards. The information on each index card was limited to an illustration of an event or emotional experience expressed by the respondent. The cards were loosely sorted into categories as the transfer of information proceeded.

Once comprehension was achieved, synthesis followed. "Indications that the stage of synthesis has been reached are the ability to provide, with confidence, composite descriptions of how people act ... [and] provide specific stories as examples to illustrate the generalization" (Morse & Field, 1995, p.127). Once the index cards were completed and sorted into similar categories, the relationships between the categories were explored. This was a time-consuming process as several re-groupings were required before the researcher was satisfied that the formulation adequately described the caregivers' experiences overall. Analysis was considered complete when the organization of categories had been reviewed and found to hold true to the researcher's overall impression of the caregiving experience, and were reasonably consistent across all interviews.

In the present study, the survivor's return home and caregivers' subsequent efforts to rebuild their own, and the survivors', lives were the two broad themes linking other, smaller categories. The following chapter presents the findings in a way that shows the consistency of these themes across the interviews while also preserving the uniqueness of caregivers' experiences.

Rigour

Rigour, or soundness, in a qualitative study is established through adherence to four principles analagous to the concepts of validity and reliability in quantitative research. The principles of rigour, first delineated by Y. Lincoln and E. Guba in 1985 have been represented under various titles by a host of researchers. Marshall and Rossman (1995) present them as credibility, transferability, dependability, and confirmability.

Credibility is achieved when it can be shown that the subject of inquiry, in this case the caregiving experience, has been accurately identified and described (Marshall & Rossman, 1995). In this study credibility has been established through the liberal use of excerpts from the interview transcripts. These verbatim accounts satisfy the need to show that, "within the parameters of that setting, population, and theoretical framework, the research will be valid" (Marshall & Rossman, 1995, p. 143). In this study, the parameters are a strengths-based approach to describing the caregiving experiences of individuals who have been providing care, in their home, to an adult family member with traumatic brain injury and who appear to be faring well in that role.

Transferability refers to the applicability of the findings to another population with similar, but not the same characteristics as the study population. According to Marshall and Rossman (1995) the burden of proof of transferability lies with the investigator who would wish to make the comparison. The researcher's responsibility is to clearly state the parameters of the research and report any atypical cases where findings do not fit the themes or constructs developed to explain the data (Mays and Pope, 1996, pp.14-15). In this study, the use of multiple excerpts to illustrate themes in the data shows nuances in the subjects' experiences. Where notable exceptions occurred, these have been addressed. Frequency, though not numerically stated, has been conveyed through the use of descriptors such as "some," "many," "a majority," "not all," etc. The fit of the data to different cultures, genders and age groups is addressed in the section on limitations which follows.

Dependability and confirmability are attained when it is reasonably established that another researcher could arrive at the same conclusions from the data. The researcher must document any changes in the design that arose out of an increased understanding of the phenomena (Marshall & Rossman, 1995, p. 145). In this study, a major shift in design occurred after the sample for the telephone interviews was drawn. When it became apparent that a sufficient sample size would not be attained for statistical analysis of the quantitative data, the qualitative dimensions of the survey (e.g. open-ended questions) were given closer consideration, and these, as opposed to demographic data were used to establish a line of questioning to be used in the face to face interviews.

Confirmability is attained if the findings are confirmed by another individual to be accurate. In this study, a sample of the taped interviews was provided to another individual on the research team along with a draft of the author's interpretation of the findings. The author and co-researcher discussed the thematic groupings, how they were derived, any unique or contradictory findings, potential recommendations, and possible other explanations that had not been considered. This led to a process of revision and testing of multiple explanatory schemes (thematic groupings) until one was found which best fit with the raw data.

Other balances against potential researcher bias in this study (Morse and Field, 1995) included documenting the researcher's thoughts and impressions as they occurred throughout the interviewing process, and continually checking thematic schemes against each interview that was conducted to examine consistency and look for atypical cases.

Limitations

Having satisfied the criteria for rigourous methodology in a qualitative study does not necessarily support generalization of the findings to a larger, or different population. This limitation and the inability to exactly replicate qualitative studies are often cited as weaknesses in the qualitative approach (Marshall & Rossman, 1995), even though they also exist in quantitative research (Semlyen, Summers & Barnes, 1998). Provided assurances are made against inaccurate or biased interpretation, such criticisms overlook the value of the qualitative approach as a tool of exploration, intended to generate new information and problems through observation rather than through previous research. As Marshall and Rossman state, a qualitative study "is an exploration, not merely a study to find contextual data to verify old theories" (p. 147). Criteria for rigour provide assurances that the new insights being proposed are a reasonably accurate depiction of the participant's view of reality at the time the data were gathered.

Given the inherent subjective nature of qualitative research methods, key limitations which should be noted are those which may have contributed to bias, either in the subject's reporting of her/his experiences or in the researcher's documentation and interpretation of them. In the present study, the researcher was a female in her early

thirties, educated in the social sciences, with several years of employment in health related fields. The researcher was conducting the study in partial fulfillment of a Master's degree in Population Health. It is possible that the researcher's age had an impact on the comfort level of caregivers who were several years older and who, in some cases, would have been caring for a son or daughter close to the researcher's age. Gender and cultural differences occurred in two interviews and may also have affected the participant's level of comfort in confiding in the interviewer.

Researcher experience was also an important factor, resulting in differences in the quality of data as skills and comfort level increased. In initial interviews it was difficult to arrange a setting where the survivor or other family members would not be within hearing distance. The necessity for privacy was made clearer as interviews progressed.

Interviews ranged from 45 minutes to just under two hours which is a limited amount of time to gain a clear understanding of a participant's circumstances. A second interview would have been valuable to confirm the researcher's initial impressions.

It is also possible for bias to be introduced through the researcher's assumptions which shape the framing of the research problem and the choice of methods and questions used to investigate it. Key assumptions shaping this study were that a strengths-based approach is appropriate for investigating the phenomenon of caregiving and that a scale (The Caregiver Well-Being Scale) administered by telephone would be adequate in distinguishing those caregivers with a high level of well-being from those with a comparatively lower level of well-being. The researcher also made the assumption, while drawing the sample for the telephone interviews, that the experiences of caregivers providing care in their home would be substantially different than those who were supporting someone in a long term care facility. The researcher had a basic understanding of caregiving demands and the lack of supports available in the community for caregivers and survivors.

Finally, the sample size in the face to face interviews is not large enough to generalize findings to the larger population without closely considering the parameters of this study, which have been discussed above. The value of the findings are limited to providing new information about a specific population that previously has not been well

represented in research. The findings yield a number of important considerations for professionals, policy makers and researchers which would warrant further investigation prior to implementing policy or program changes.

These limitations are important to keep in mind as the reader approaches the researcher's discussion of the findings.

This chapter presents the results of interviews conducted with nine caregivers of adult family members with brain injury. All survivors had been living with the caregiver since their discharge from the Brain Injury Rehabilitation Program, though three had recently moved to a separate residence.

The themes and sub-themes which emerged from the data fell into two broad categories representing major transitions in the caregiving arrangement. The first category includes themes which describe factors that influenced caregivers' decision to care for their injured family member in their home. Three factors were consistently mentioned by respondents. These are: a sense of familial responsibility; a lack of alternative care arrangements; and the survivor's longing to return home.

A second, and larger category concerned respondents' common experiences around the process of rebuilding their lives. Themes emerged which describe caregivers' adjustment to loss and changed roles and responsibilities, their recovery expectations and goals around the survivor's future independence, how they managed to 'have a life' by setting personal boundaries on the physical and mental demands of caregiving, and finally, how they maintained the strength to continue providing care over a period of several years.

Three unexpected cases where the survivor had moved out of the caregiver's home since the initial telephone survey, provide some insight into a possible third transition in the caregiving relationship.

Findings are presented in this chapter as objectively as possible. Though the creation of themes was driven by the research questions, results are presented in a way that provides as complete a picture as possible of the caregiving experience through the respondents' own words. This is accomplished by introducing each theme only briefly and heavily supplementing the text with excerpts from the interview transcripts. This format is typical of the writing style used in reporting the findings of phenomenological research, wherein the object is to "describe the essence of behavior" (Morse & Field, 1995, p. 22). The researcher's interpretation of the findings follows in the Discussion chapter.

Coming Home

The first question respondents were asked in the interview was "How did you become [name's] caregiver?" The purpose of this question was to solicit information describing such things as the respondent's perception of the caregiving role, when her/his role as a caregiver began, and what aspects of the caregiving experience were most significant to her/him. Eight out of nine caregivers initially responded with references to the time when the survivor was discharged from the inpatient rehabilitation program in Ponoka, Alberta. This consistency warranted creating a theme to encompass their experiences during this important transition.

The second level of thematic analysis produced three sub-themes for the most commonly mentioned factors leading to respondents' decision to bring their family member home. These are: a sense of familial responsibility; a lack of alternative care arrangements; and the survivor's longing to return home.

Familial responsibility

Based on the frequency and intensity of caregivers' responses, a sense of familial responsibility was clearly a major factor supporting their decision to accept the role of caregiver to their injured family member in their own home. It is significant to note that five of the nine survivors in this study had been living with the caregiver at the time of the injury (two were married couples). One had very recently moved out on her own and another two appeared to be living intermittently with the caregiver. Only one had been living entirely on his own for some time. All nine respondents made reference in some manner to their duty as a parent, sibling or spouse to care for the survivor. Four had this to say:

"So we thought, there's no way we're gonna – it wasn't so much there was no way we're gonna pay somebody else to do it. We felt at that time it was our duty to do it. You know, we should do it, and that's it."

"Well, as I said, I love my son, and I've been with him ever since the accident – I was beside him."

"Just being his wife. [Pause] I guess it's just something you have to do ... Like, a lot of people would probably just walk away, 'Can't do it anymore,' but you have to, you have to stay with it. I want our family to stay together."

"Well, I guess marriage would be the main reason, and [pause] yes, I guess marriage would be the only reason. If I wasn't married to him, I don't imagine I would be – noone would be around him."

In the one instance of sibling caregiving in this study, familial responsibility was less clearly evoked, but was equally apparent in the lengths to which the caregiver went to ensure his brother was getting the help he needed. In many cases, the fraternal relationship complicated the caregiving relationship, as illustrated in this excerpt:

"...he doesn't want to work with me anymore ... I told him a hundred times, if it's not me, then it's gonna be somebody else. Then he says, 'Well no, I don't want a public guardian. I'd rather you.' Then every month it's a fight over his money."

While respondents' comments consistently revealed a common sense of familial responsibility, their emotions and reasoning behind their commitment were highly varied, ranging from those who reasoned that it was their role and their desire to keep the family or the relationship together, to others who were frightened by or dissatisfied with the alternatives.

Lack of alternatives

Though the sense of familial responsibility was predominant, it did not entirely override respondents' consideration of other care arrangements. They did, however, describe those options as limited or unsatisfactory. As one caregiver stated, *"It was a*

foregone conclusion that we would bring our son home ... There was nowhere else for him to go."

This caregiver went on to describe two subsequent and short-lived attempts to transfer her son to a group home setting. Her experiences led her to feel that the system is "warehousing people."

Several other caregivers described troubling experiences with long term care facilities and group homes.

"...they didn't know what to do with him...this girl who was the head of the program, she didn't know what kind of exercises to give our son and blah, blah, blah. There was a lot of wasted time there and it's a time I'd rather forget all about."

"They tried to move my son into a place over here for a couple of weeks so I could take a break. I did, and he went crazy over there. He didn't like it. He got mad and everything...there's more old people in there."

"I was worried he was gonna end up in [facility name] forever, 'cause he is a little violent...so I was afraid to put him in a group home...[afraid] that he'd freak out on somebody and then they'd lock him up and say he's totally nuts. So that was my main concern. That's the main reason I kept hanging in there mentally."

"When she was at [facility name] they changed her Depends supposedly once every shift, or twice every shift, but they didn't <u>really</u>. She wasn't getting the attention."

Several other caregivers felt that they could provide better care at home, and that the survivor would make better progress at home than in an institutional setting. One caregiver felt that her daughter was suffering emotionally by being away from home, and because of this was regressing.

"...she started to lose her memory and forget people that she knew when she was there [at the facility]. It was really a concern. She wasn't sleeping. I think it was because she wasn't at home...Because of what was happening to her with going backward we thought, 'No, this isn't a great place for her. She would do better at home with therapy than with us driving out [to the facility],' and she did. Emotionally she did better, and then she started picking up better."

Another caregiver also attributed her son's emotional distress to being away from home. She described feeling angry that he was kept locked in his wheelchair and given medication to control his behavior while in the facility.

"They couldn't control him over there. They got him back there, they put him on tranquilizers. Boy that just made me mad. 'Cause I took all the medication off him after he got home."

Survivor longing

The comments excerpted in the previous section not only illustrate some caregivers' desire to bring their family member home, but suggest that survivors wished to return home as well. Survivors' longing and demands were a very prominent factor in the home-coming decision, as these quotes illustrate:

Every time we went down to visit, it was 'I want to come home.' And we'd get this every time. And every time we took him back on a Sunday and left him, it was just – sometimes we went through hell. So then we decided, 'Okay, we're going to do something about it."

"...if I had really had a choice, I'd have left him there. But that probably wasn't very – he wouldn't. He was ready to come out, sort of putting pressure on me to come out."

"...he didn't want to stay. He said they're all crazy in there. But he'd been in hospital for three months, so it's kind of understandable."

"The reason she was discharged was because she really couldn't stand the place – became rather suicidal, actually – and said if we didn't get her home, she was going to do herself in. Even though she probably would have benefited from quite a few more months of therapy, we brought her home."

As the final excerpt shows, the survivor's longing to be at home at times overrode the need for additional rehabilitation. Another caregiver in a similar situation was given the option to re-admit her daughter back to the rehabilitation facility.

"She wanted to leave so bad and she was getting very, very depressed there. So the doctor said, chances are, because of the state of mind she was in – her being depressed because she couldn't go home – they felt she probably wouldn't progress a lot in there, so maybe it would be better to come home. But they left it open that she could go back if ever the need be, and they'd probably take her back in if she needed it."

Survivor longing also overrode fears and insecurities that caregivers had about bringing the survivor home. These included concerns about obtaining outside care, uncertainty about their ability to meet the challenges of caregiving, and worries about the survivor's safety and well-being while living at home.

"It was very hard, because you get into an established routine, and I was quite happy with what the hospital was doing…in some ways it's easier when they're at home, but it's <u>scarier</u> because you're not sure you can handle things. Not sure if you're going to get help, not sure if you'll really like the help you get."

"[I thought] 'Oh boy, here we go. Now the challenge is on.' Because I had those months with my kids and myself, and I was doing everything and it felt good that I had that independence."

"…I was also so scared that he would try to go down the basement stairs, remembering that that's where his bedroom was. So what I used to do, before we went to bed, I put the — there's a storage bin, I had it there ….I would put that at the door to the basement stairs, and I'd put a bag of something else on top. So if we were sleeping and he opened this door, I would hear him, you see. I was so scared he'd fall downstairs."

"It's like we were deciding for the rest of her therapy what was right for her, and that was really hard."

For the final caregiver cited above, insecurities about the wisdom and long-term outcome of her decision were allayed by a strong sense that, in the end, it was the only viable option.

"I'm still glad we did it [brought her home], because I'm sure she would have died out there [pause] mentally died. Not physically, but mentally. She would have given up."

Rebuilding

Recovery from brain injury is frequently described as a process of rebuilding one's life. While the term is often used to describe the experiences of survivors of brain injury, families and caregivers are also faced with dramatic change and the need to "rebuild." Rebuilding is an appropriate term to describe the experiences of the nine caregivers who participated in this phase of the study.

Respondents' discussion of the Rebuilding process yielded a number of themes and sub-themes. These have been organized as follows. The four major themes describing important rebuilding processes are: adjustment; setting goals; setting personal boundaries; and staying strong. Within the scope of "adjustment" are narratives describing adjustment to loss and adjustment to new responsibilities. As a category, "setting goals" comprises the thoughts and activities of caregivers as they developed goals and expectations about the survivor's recovery and her/his ability to be independent. The third category, "setting personal boundaries," encompasses caregivers' comments around

the importance of having their own life by creating time and space away from the survivor and finding peace of mind. The fourth grouping, "staying strong" describes challenges to caregivers' physical and mental well-being over the long term, and how caregivers found the strength to persist. Wherever possible, each category presents evidence to show the importance of these processes to the survivor and what enabled them to succeed at each.

Adjusting

Respondents described many ways in which their lives changed once their injured family member returned home. Several spoke of the adjustments they had to make to the loss of a job, friendships that were important to them, or a lifestyle that they could no longer maintain due limited time and money. Several others spoke of the fears and insecurities that accompanied taking on a whole new, and extensive, set of responsibilities. Caregivers descriptions suggested that over time, many had found ways to adjust their lifestyle to accommodate the changes. As one caregiver put it, "change can be positive." Even with time, however, there were still changes that evoked sadness in caregivers, particularly when they recalled the way things 'used to be.'

Adjusting to loss. A very dramatic and traumatic loss experienced by any family member of someone with a brain injury is the loss of who the survivor once was. The loss of social skills and ensuing isolation was most frequently referred to. These changes led to increased conflict between the survivor and others (such as family, friends, strangers), and a decrease in activities that the caregiver and survivor once shared together (such as going out, spending time with family). Most caregivers were clear to state that in spite of dramatic behavioural changes in the survivor, there were certain core elements of that person's identity that remained. Being able to recognize this seemed to be one way caregivers coped with this major adjustment.

"If you know that person, you know some of that personality is still there, and [our daughter] still has a lot of her old personality. They never lose — like, she's never lost her stubbornness and her 'I'm gonna do this' and there's still likes that they have from

when, before their brain injury, that they never lose. So basically, there's still that person there, and you know that person is there. Even though their temper may be a little bit shorter —"

Other caregivers were able to identify ways that the survivor's behaviour or personality had changed for the better, and this too, seemed to give some comfort.

" [Before the injury] He [survivor] was somewhat dependent on alcohol, and that worried me. He was on pills for depression and that always worried me. I always wondered where were we going to go with this ... After the accident ... [it was] Cold turkey! Yeah. It was cold turkey. No drinks. He wasn't on alcohol any more. Just [pause] like that!"

Others adjusted to negative behavioural changes by changing their own habits, such as the following caregiver, who responded to her husband's inappropriate behaviour by going out less, or going out alone:

"I certainly have a lot less __fun__ in life. Because you don't go out." "I mean, my husband used to be the life of the party. Even when we were first married, he did drink, but it was at social events and he always ... and then afterwards [after the injury], he got so that he'd be mean and ugly and miserable and belligerent about driving home. So a change in that way. So it's easier not to go out with him."

Parent caregivers spoke often about the loss of their daughter or son's "social circle." The loss of old friendships and difficulty making new ones is common for people with brain injury. A number of parent caregivers stated that their son or daughter did not wish to associate with other brain injured people. Caregivers responded differently to this, with one caregiver stating that as a result, her and her husband had become her daughter's primary source of social activity:

"...most of her friends have gone their own way, so [my husband] and I are sort of her social circle, as well. So we [pause] really feel guilty if we go places without her. She goes [pause] most places that we go."

Something which appeared to help this caregiver cope with her daughter's social isolation was her daughter's participation in sports. The caregiver did much to encourage her on-going involvement, and was proud of her accomplishments in this area.

Even after time, the changes in the survivors' abilities and personality caused a great deal of hurt, with some caregivers becoming teary-eyed when they recalled that their family member would never be the same again.

"I'll never see him bound up those stairs toward me again ..."

"It's not very much that I said, not very much to talk about what I come through — through all my life. It's not new to me. The only thing new to me is watching my son like that. That's new to me and I don't like it, but what can I do? Sometimes, I wish that he can remember a little bit at least. That's my wish, but I don't know. Long time, 5 years. But he's still strong."

Caregivers also spoke of the loss of work, friendships, or lifestyle that followed their family member's return home. Again, caregivers made adjustments to these changes over time. Some described how they adapted their previous activities to fit their new caregiving demands, such as one respondent, who began operating her business from her home after her daughter was discharged from rehabilitation. Though she missed her relationships with her co-workers, the arrangement gave her the ability to maintain a profession she clearly enjoyed.

Another respondent who had been working full-time decided to return to University when her injured daughter decided that she wanted to go back to school:

"[Our daughter] was determined that she was going to go back to University ... I was partly through my degree at that point, and I decided, well, that if I was going to be transporting her back and forth to University, I might as well be going myself. So that worked out well. I could adjust my courses around her schedule, so we both became students again."

Another described how she had taken three vacations prior to her son's injury. Rather than viewing it as a loss that she may not be able to travel as freely, she approached it as preparation for the traumatic changes she would soon face:

"It's funny — the year before [our son]'s accident, we were on three trips that year ... The girls at work were saying, 'Three trips in one year! I don't know how it's done. How'd you get enough money to do that?' You know, teasing us. I says, 'Listen: three trips in one year — I'll take it and I'll enjoy it, because who knows when it's going to stop?' And it was the following year [our son was injured]."

Adjusting to new responsibilities. Respondents described a number of new and challenging responsibilities that came with caring for their injured family member at home. Many spoke about assisting the survivor with relearning skills (e.g., speech, social skills, life skills) and the need to constantly monitor her/his actions to prevent injury or to assist in completing simple tasks.

A surprising number of caregivers often described these responsibilities within the more familiar context of parenting a young child.

"It's just the same as when you have kids and your kids are growing up, and learning different things and getting out to play and have fun. You're doing it now – the same thing again – but you're doing it with an adult. I mean, a kid accepts that 'You can't go here. No, you shouldn't do that' ... an adult doesn't accept ... that's the hardest part."

"They're just like kids. You have to teach them. You have to teach them all over."

"[It's the same as having children] only more responsibility ... our daughter is more of a thinking person. She's more of an individual. She knows what she wants and what she doesn't like ... so it's like having another teenager around but one that's dependent on you to watch out for her well-being all the time. That's a big responsibility!"

"... in some ways, I've switched from being a wife to a mother. Changed roles ... he calls me 'mom' all the time, and it's been more significant, so that you're not in a relationship with two people sharing and that ... it's more like a parent looking after a kid. In a lot of ways he's pretty high functioning, and in other ways, he isn't."

With respect to relearning, caregivers focused very much on improving the survivor's social skills.

"We started taking her out to the malls when she was being tube-fed and in diapers. People would look, and it was kind of funny, because people were actually very nice and concerned ... open doors and stuff. So it's, like, don't be asha— take them out. Don't just lock them up in a room and ignore them. Take them out."

"And then, we were associating with older people ... We've got a lot of friends. So the older ones, we got to be with all the time, and I loved them dearly. We all did. But the kids were starting to get depressed, and I was starting to feel like [pause] I need more than just older people. It's dragging us down. And [my husband] was — he was just in his own little world and he was loving it, but he didn't realize how it was affecting us. So I finally told him. I said, "[Name], we love those friends and we don't want to exclude them. We want to keep them in our life, but can we broaden out? Can we get friends for the kids, our age and in between?" and all that sort of thing. So he did."

"He [survivor] has a tendency to reach out and touch people when he's talking to them. I asked him to put himself in their position. 'Understand, [Name], that if someone was talking to me and reached out and touched me, what would you think? You would think

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that that was inappropriate.' And he would say 'Yes'. That's how I got him to understand that it wasn't appropriate for him to reach out and touch people when he's talking to them."

Another facet of the adjustment to new responsibilities involved caregivers role in supporting the survivor's general recovery. In this capacity, they saw themselves as teachers, coaches, and advocates. Caregivers placed a great deal of importance on their responsibility to perform these roles.

"Once she got able to drive ... her first long trip was out to [town name] ... I wrote her out directions and drew her a diagram ... I wrote exactly what each sign said, so when she went, she knew exactly what to look for. And the same coming home."

"...he's the athlete and you're the cheerleader behind him, and that's exactly what they need."

"I'm constantly encouraging him. That's why we kept him alive, and I will never stop encouraging him."

"I think in this day and age, you definitely have to be prepared to be an advocate for your daughter ... making sure that she's able to do everything that she should be able to do."

Caregivers' adjustment to these responsibilities was facilitated by their own sense of self-confidence and ingenuity. As one caregiver declared: *"Inventive! You had to be really inventive with different things."*

At other times, caregivers simply did what they could and hoped for the best.

"And we were putting little drops of orange juice — drops — just drops, in her mouth, for taste. I don't know if that did anything with her brain injury, whether it helped her brain restructure ... I have no idea. But that's what we did."

"I'm going to try and rig him [survivor] up with a cab company in case [he gets lost] ... so if that happens he doesn't have to phone an ambulance. You know, have a credit, little credit line for him every month..."

Setting Goals

While required to adjust to factors beyond their control, caregivers still exercised a measure of control in their lives by setting goals for their family members' recovery, and for their future independence. Through their narratives, it became apparent that these goals were influenced by strong values and a clear sense of how they wanted their life to be. One caregiver, whose goal was to keep her family together after her husband's injury, spoke of her feelings this way:

"I have this thing, especially since [my husband]'s accident, I thought life as a family does not have to be drudgery. It should be fun and — not always — I mean, we're always going to have our moods and this and that, you know. But I think, I want my kids to not dread coming home..."

Many had adjusted their perception of how life could be, but still had clear goals and expectations for the survivor's improvement. All clearly held to the belief that their family member deserved every chance to recover, and to experience some measure of independence in their life.

Setting goals for recovery. All survivor's stories contained expectations around their injured family member's potential for recovery. In many cases they were disheartened by what they perceived as the negative prognoses of health professionals. In the words of one caregiver:

"I remember the person I still have the most anger for is the social worker in acute care that just flatly told us that we'd better be prepared for a daughter who would never be able to look after herself again .. [that] she'd be in a wheelchair the rest of her life. This, sort of out of the blue, really was very upsetting. When I think back, I think it was just __so__ unnecessary ... I understand, from a medical point of view, that doctors and nurses don't want to give false hope, but on the other hand, I think they can give a range – there is a possibility that they may do quite well, depending on the individual."

Only one caregiver reported that professionals, in this case the rehab team, were helpful in helping her establish realistic expectations and remaining hopeful.

"They always say that the different phases that the patient goes through — you know, since the accident, they go through certain phases, and it's a long time before they get to the phase of acceptance of what's happened to them. At [the rehab centre], I said to that psychologist, 'I think he's at that phase right now.' She says, 'I don't think he is.' ... Boy! Was I — was I ever wrong!" *"But once [our son] come home, we thought, well, he wants to [go to his old bedroom], but he can't because he could never make it up the stairs ... Then the guy [at the rehab centre] told us, he says, 'He will walk,' he says, 'because never once has he tried to move that wheelchair with his hands.' Never once. So they took the foot steps off and he moved with his feet. So he says, 'He will walk.'"*

A smaller number of caregivers spoke of receiving negative feedback from friends, family, and employers.

"One lady I work with I've pulled away from, because she's always saying to me, 'When are you putting him in a home?' So sometimes, friends are not good people to talk to."

"We have relatives who say we're scamming the government ... that [my husband] could go to work ... But nobody understands that if he were to go to work, it could __really__ turn our family life upside down ..."

"So then when she got her separation slip [from her employer], it said the reason for letting her go was due to illness or injury ... [it wasn't fair because] I know that our daughter would be – she'd try hard and probably do whatever she's asked. She might be a little slow at doing something, but I'm sure she would do that."

Most caregivers responded to negative feedback and predictions by strengthening their resolve. Several stated that it required great strength to stand up to others, and that this ability was key to their success.

"...nothing's going to stop me if I want to do something, because all I have, in [my] mind. I had that ever since [I was a child]. I'm not scared of nothing."

"Most people in our situation are afraid to speak up. I've never been afraid, and my husband has never been afraid, to speak up to doctors and tell them how we're feeling. A doctor told me once that I was threatening his professional authority, and I said, 'Of course not. I have a right to disagree.'"

Most caregivers in this study reported that they received negative and disheartening information from health professionals at the hospital, and sometimes also in rehabilitation. In retrospect, they felt that these negative prognoses were unfair and inaccurate. Given the negative feedback or a general lack of information about brain injury outcomes, caregivers more often based their recovery goals on other sources, such as experimentation, and faith in the survivor's continued ability to improve.

"Over Christmas holidays, when she was home, we actually taught her how to speak. We didn't know if she could understand or not, so it was all a guess. The only thing she could say was 'okay.' Everything was 'okay.'"

"I thought to myself, if [our daughter] would just get to that stage ... if she was just able to take just one step, I wouldn't ask for anything more. But it's not enough! [Laughs] We

know there's more in there. So it's going to come out, one way or the other. I guess I was fooling myself when I say I'd like her to be able to at least be able to try and speak. Now I think she should be able to speak more fluently, a lot clearer, if she puts her mind to it..."

"You know, they [survivors] make strides and do different things. Then all of a sudden, for a little while, they'll just kind of straighten out and there's nothing much happening. Then all of a sudden, away they go again."

A great deal of hope seemed to help caregivers maintain a positive perspective toward recovery. Signs of the survivor's improvement, even those that were very small, were crucial to maintaining hope, as were signs that the survivor was willing to change.

"... when he went into the [rehab centre], he couldn't walk, couldn't talk, couldn't feed himself, and he was just like [pause] he couldn't do anything ... Within a couple of weeks in there, he was walking ... talking, starting to play cards..."

"... people would say ... 'I can't see your son ever doing that.' But we could – or hoped he could ... My husband used to say that the bit that scared him was, at a certain point, this was as far as our son would go. I says, 'Who knows where he'll finish up? I have no idea.'" "I used to talk to the girls at work and say that [our son] would do such-and-such a thing — "Oh, yeah, yeah." I knew fine — I stopped doing it, because I knew fine when they said that, they thought I was getting carried away, you know? It's no big deal about that. But they don't realize how much — I mean, it comes naturally to a kid, a baby. It doesn't come natural to an adult. You have to relearn everything."

"I'm trying to keep the relationship the way it's supposed to be, so that we're friends and we're mates, you know. He's trying. He's trying really hard to let it be the way it's supposed to, and he finds it hard at times, so he just tells me to be patient."

Some caregivers described how their expectations evolved, and their confidence in the survivor's capabilities grew over time:

"For a while ... I try and leave him by himself in the day — I have to find a baby-sitter. That's when he first came back [from the rehab centre]. Then slowly, I started noticing him, more and more, how he should become dependable, what he could do for himself."

"I don't think we give him enough credit for what he can do. Scared to leave him and scared to think what would happen. Well, nothing happened."

Though there continued to be struggles and challenges, most caregivers appeared to be coping well with the survivor's current level of functioning. This was not the case for one survivor, who was continuing to experience numerous "failures" and set-backs in trying to help the survivor toward recovery. After being told there was little hope for the survivor, this caregiver set out independently to try and resolve the survivor's drinking problem and lack of motivation. Unfortunately there were few positive results for this effort.

"... it's almost getting to the point where it's out of my control, 'cause he doesn't want to work with me any more. He thinks I'm ruining his life, I'm controlling him and his money, and that. I told him a hundred times, if it's not me, then it's gonna be somebody else."

This example, though an exception to the other interviews, suggests that there is a strong relationship between a caregiver's recovery expectations and their ability to provide care over the long-term.

Setting goals for independence. Few caregivers in this study reported being supported by health professionals to envision an independent life for their injured family member. Most caregivers were vague in describing what they meant by "independence,"

whether this meant living alone, in a group home setting, or in another supported living environment. In spite of this, it was clearly very important to caregiver respondents that their family member be prepared to live without their ongoing care and support.

Many parent caregivers expressed their fears about the future.

"Our greatest fear right now is that when we die, what's going to happen to [our daughter]?"

"Biggest challenge, I think, is, to me – a challenge or a worry, actually – if something happens to us [husband and I], what's going to happen to our son."

At the same time, fear was also involved in learning to let their loved one do things on their own.

"So when he left for the bus [on his own] that first day, I just died. I phoned my daughter. She knew what was happening ... Well, she got all the girls in the office, and they're all sitting, crying ... when [our son] got off the bus at the transfer point, and he has to cross the street. [The guy who was there to meet him] phoned me, says, 'Okay, he's coming off the bus and he's heading over here. He's arrived.' I thought, 'Oh, he's gotta come home now!' You know? I was sick!"

Some caregivers had started making plans for the time when they would no longer be able to support their adult child.

"We still support her [financially]. She's saving the majority of her insurance settlement, hopefully to be able to buy a condo of her own. That way ... she'll be very financially well-off as she gets older ... so that's one of the reasons we're still financially supporting her at this stage."

In this study, three of the nine caregivers had already ceased to provide care in their own home. As a study of the factors that influenced this change of caregiving arrangement, it is worthwhile to briefly compare the three.

In the first case, the survivor's daughter had been living in her own apartment for several months and had more recently married. In this case, the daughter's high level of functioning was a major factor in her ability to live on her own and establish healthy relationships. Nevertheless, she continued to phone and visit her parents frequently, and the caregiver reported that she still was very much involved in her daughter's life. For this caregiver, her daughter's transition to independence was a positive experience.

"...to see her in her dress and standing, being married and to think – wow! To think that it would ever get this far, you know. It was like a miracle in itself. And to see her happy. Made me cry!" " I told him [daughter's husband] that — I said, 'Boy, am I ever glad you're taking her over, because,' I said, 'now you can do all the reminders to keep appointments and stuff like that.' 'Cause she does need lots of reminders, if it's something she has to do, or appointments, something like that."

In the second case, the caregiver's son had recovered well physically, but still experienced an extremely compromised short-term memory and had some behavioural difficulties which required him to be accompanied at all times. After several "failed recoveries," as she called them, she had reached a point where she could no longer deal with the repeated set-backs and demands on her life. She and her husband began a long difficult process of advocating for funding to provide her son with 24-hour care in his own home. Though the process had been very long and fraught with difficulties, this caregiver also was able to describe her son's eventual independence as a positive outcome.

"I've felt best in the last month, since [our son] has moved into his own home. I was worried that he might not accept living anywhere but home, but now that he's moved in, he's very happy, very content, and it's been a big step forward for him, because he'd become totally dependent on me. We've always had a very close relationship, but since

he'd been living at home, he was dependent on me for every decision and everything that he would do... Now that he's living on his own, he's a kind of boss to his caregivers ... he has some authority in that way. When he was living at home he gave up those rights to me."

In the final example, the caregiver had made several attempts at encouraging the survivor to overcome his drinking problem and become more motivated. Unfortunately, these efforts were not met with success. The survivor eventually moved out under conditions of tension and conflict. The caregiver remained very involved in supporting the survivor's independence but was having great difficulties, particularly where control over money was concerned.

"I never took a trusteeship because I figured he should have some kind of independence, some kind of say. But that hasn't worked out so good because every month, there's a fight, kind of thing, to pay his rent and all."

In these three cases independence was associated with very different outcomes. A closer examination of the data from the three interviews offers some possible explanations for the differences. First of all, the survivor's level of functioning had an influence on independence, with behavioural problems reducing the ability of survivor's to manage on their own. Another difference lay in the quality of the relationship between caregiver and survivor prior to the injury. The caregivers in the first two examples stated that they had very good relationships with their children whereas the third caregiver had had a strained relationship with the survivor for some time ("he'd been bumming off us for years"). This may have influenced the ability or desire to manage the challenges associated with independence.

Another factor may be the amount of family and social support the caregivers accessed during the transition to independence, though this factor was not entirely clear in the data.

A clear distinction did exist however, in the type and amount of professional support which the caregivers accessed. Professional support was critical to independence in examples two and three, where significant behavioural issues prevented the survivor from being able to live alone successfully. In both cases, the caregivers were very determined to find support for the survivor. The caregiver in the third example had accessed several community and provincial agencies. In contrast, the second caregiver had gone beyond the limitations of the existing system to demand appropriate care and funding, and had support from others (e.g., her spouse) to do this. This process proved very long and difficult, however it clearly meant the difference between their son's successful independence and a very uncertain future for both him and his parents.

"He's in a safe place now. This is very important to me that he not become a statistic – one of those people who ends up living on the street. Now he's in his own home, and his kids are still a part of his life, and he's content there."

When asked what advice she would have for others who were just starting out as caregivers for adults with brain injury, she declared:

"Start looking for funding, because you cannot do it forever. Don't stop fighting.

Setting personal boundaries

All the caregivers in this study exhibited a high degree of tolerance, patience, persistence and flexibility. These characteristics enabled them to make dramatic adjustments in their lives and work toward goals, often with minimal outside support. The most significant outcome that seemed to come from caregiver's ability to set personal boundaries was that they were able to feel once again that they had a life of their own.

"I think you need a life of your own. You can't be totally wrapped up with the other person. If you are, I don't know how you can totally handle it."

For some, the line was drawn between their caregiving responsibilities and their need to maintain healthy relationships with the rest of their family. Several noted that they did not wish to see their family negatively affected.

"...here [at home], he has no respect for me, for [my spouse] ... I mean, I just can't keep going like that where I've been fighting with [spouse] for a few years, now." "Probably, if it'd been just me, myself, I could have put up with it longer, but it was a chore for them [the rest of the family]."

"My husband and I never asked our other kids to give up their lives to care for [our son]. You can't expect family and other people to do that ... they have other things they have to do ... When you make the choice to be a caregiver, if that's your commitment, you have to take it. Don't think for a minute that others will help. Even if they say they'll help, they may not be able to, even if they want to."

Though caregivers were willing to take sole responsibility for the survivor's well-being, they also set limits on how much of themselves they were willing to sacrifice. They told how they had set physical limits by putting time and space between themselves and the survivor, and how they created mental limits that enabled them to achieve peace of mind.

Finding time and space. Caregivers created time and space away from the survivor in several ways. Work was a common way that caregivers created time away from their injured family member.

"... to tell you the truth, at this stage, I think I really do need to work. I think that my daughter and I would probably have a much more difficult time if I were home 24 hours a day when she was home, and it would be harder to get along. I need my space and she needs her space away from us, too."

Work also contributed to one caregiver's sense of self-worth.

"The staff that I work with give me lots of positive feedback and that kind of — I work overtime because people come in and want to talk about problems, and I think I'll really miss that people contact [when I retire]." "Acceptance at work for what I do is a very positive thing."

Even small amounts of time alone were valued in situations where caregiving demands were high.

"[What's the] Best thing that's happened? I have more time. I have more independent time. Like, I can do things that I want to do now. It's not — [our daughter] can work out and I can be doing something totally different. I can actually clean the house now, once in a while. [Laughs] Yeah. More time [pause] is one of the best things that's happened since then. I can't think of anything [pause] except for [pause] more time."

Other caregivers described how they created separate spaces for themselves and the survivor within their own home:

"... if he [survivor] gets irritable or annoyed with me at times, so I need to get outside or something. That's kind of why I wanted a basement ... because [pause] it's for separation."

"He's pretty well independent downstairs in his room ... I never touch his bedroom. I never did it before — never ever did his bedroom or did his laundry. [Our son] always looked after himself and he still does. He's back doing his laundry, his does his vacuuming. I don't touch downstairs ... He likes the responsibility of doing downstairs, so — helps me!" "I've got to give him his space. He wants his own space. If I crowd him too much, well, then I get on his nerves, and he gets on my nerves. It works both ways."

Another caregiver stated that she was comfortable spending a lot of time with her husband, but that she gave him space when it came to pursuing his hobbies.

"My husband's into the kitchen. He's baking bread and [laughs] he cooks and makes noodles, his own noodles, by hand. He doesn't use a machine. [Laughs] So I just back out and I let him do it, because it's something that he's found that he enjoys."

Caregiver's narratives showed that they valued time and space away from the demands of caregiving, not because it allowed them to take care of daily tasks such as grocery shopping or cleaning, but because it allowed them to do things that they truly enjoyed – things that were once a normal part of their life.

You just try to do what you can, and occasionally, you just have to have a break. A couple of good friends can help. I've been able to phone occasionally and say, "I really need a break. Can you go out for dinner with me?"

"— the focus is not so much on her any more. You can focus yourself on — like, with [my husband] and his business, or the animals. You can actually enjoy petting an animal, stuff like that. Whereas before, it was, no — [laughs] — too much stress."

Finding peace of mind. Finding peace of mind amidst the fatigue and frustrations of caregiving was as important to caregivers as was finding time to spend on their own. Caregivers found peace of mind in various ways. For one respondent, it depended in large part on her daughter achieving stability in her health:

"When we got her home ... [my husband] would say, 'I'll watch her. You go out and do grocery shopping.' You could go grocery shopping, but your mind wasn't there, because I was still focused on [our daughter] breathing and just being alive. Now, you're not as focused. Your brain is more open. And you can enjoy things now."

Letting go of the small things and recognizing personal limitations was a factor in avoiding mental strain for two other caregivers.

"Trying not to correct him. Like, only correcting the things that are relevant, not foolish. Like, if we're going for a drive, and if we're out driving and he'll say something about somebody who used to live here, how really important is it if I correct him? So sometimes I correct him, sometimes I just ignore it."

"You know, Mom can only do so much when there's not the greatest amount of rapport, when there's the, you know, typical mother-daughter relationship. We get along well, but -- [laughs] there is a limit to what mothers can accomplish!"

One caregiver, whose relationship with the survivor was quite tense, resolved that being a family member was a major limitation to being an effective caregiver.

I'm kind of worried if I do [give things over to a public guardian], things might not go so good for him [survivor], but it's come to the point where I think things can't go any worse. Because he won't listen. And that's a family thing. Me and [my spouse] have worked with handicaps for the last 10 years. We were like an approved group home, so, like, we know about stuff that's happening, you know. Family's not the best."

Some caregivers described finding peace of mind in spiritual awareness.

"I'm more at peace with life ... Spiritual awareness is something that's very positive for me ... In particular, nature has something I can relate to ... [it gives you a] sort of peace, sort of the understanding that life is more than just the person yourself ... there really has to be a spiritual being sort of controlling it. I find that very peaceful."

"...we live totally, extremely by Bible principles. Then, we also have hope for the future, so, like, even for [survivor], at least we can look towards the future and know that he's not always going to be like that..."

Some caregivers found peace of mind in the company of the survivor.

"...it's just the whole freedom thing ...It's like getting out into the fresh air and smelling it and being able to move your arms and there's nothing tying them down. When we go for our walks, we talk. We really talk. We can talk about our feelings, which brings us together. And the freedom of not having to handle a phone call or even deal with the kids or housework."

For another caregiver, peace of mind appeared to come from knowing that her son was not the centre of her life.

"I've got to say this and I don't mean it with any disrespect to my son, but the home is not priority one, and neither is he priority one. He's home, he's doing his own thing, does what he wants to do, and as long as he's healthy and we're healthy, that's the main thing."

Staying strong

The ability to set personal boundaries on the physical and mental demands of caregiving required a great deal of strength on the part of caregivers. Caregivers faced numerous challenges to their strength and employed various means to maintain their physical and mental health.

Challenges. The survivors themselves were a primary source of ongoing challenges to caregivers' stamina. Behavioural problems outranked physical limitations in terms of the strain they placed on caregivers. Anger, resistance, and control issues were all mentioned.

"We had him at an anger management program ... and the guy tried to help him. He said, 'If there's a confrontation like that, you have to turn and walk away,' to [our son]. 'And if that doesn't work,' he says, 'you guys [parents] have to turn and walk away.' But if we do that, [our son] follows us. He has to — when he's angry like that, he has to have the last word, the last scream, the last shout. And when it's finished — sometimes it can last about a minute — it seems like ages."

"She doesn't want anything to do with brain-injured people. She probably resents the fact that I spend as much time [with brain injury organizations]. I also was a member of [a brain injury committee], for a while, and she really [pause] that seemed to upset her, the fact that I felt the need to [do that]."

"...he was taking control over everyone's life, even myself. Over the years, it was hard because he wouldn't let me even go shopping by myself. Then it was a big worry if I didn't tell him I went, or if I went grocery shopping too long, you know, it was pretty hard. But he was always willing to change when we really brought it to his attention. Then, every once in a while, he'd kind of slip back again and fall right into that."

A number of caregivers spoke about how they were gradually wearing out. *"The only thing, I'm getting old and not as strong as I used to be. Well, at [my age], I'm not strong. Too much work all my life, though."*

" ... [it takes] a lot of talking and a lot of thinking ... it's getting harder, now! [Laughs] I'm wearing out! [Laughs]"

"I'm over it. It's not that I don't give a damn any more, it's that I can't do this for — I know somebody else can do better. So anything that can work better. If I go 2 years and I don't gain ground, I lose ground, there's no sense in me continuing. I try and do my damnedest, but it's his attitude."

Other caregivers also noted that they experienced frustrations that were very wearing on them.

"...he[survivor] says, 'Okay, we'll have one meal out,' and he tells the kids that. We get out there, and he goes, 'But I can cook. I can get something from the grocery store and it'll be a whole lot cheaper.' And I'm, like, '[Name], you can't change' — that's a small example, but that's how he always does things. So it's always a disappointment, even if it's little. There's too many of those small disappointments because he [sigh] he's in this world of his own, that's what it is."

"It's like a death that keeps happening ... someone who hasn't been through it has no idea what an emotional pull is involved ... some days there are good days, some days there are bad days, and you go from one to the other, back and forth and back and forth ..."

Three respondents found that the survivor's inability to recognize or accept that s/he had a brain injury was a source of ongoing frustration and held up progress.

"It's been a big issue because she ... hasn't really dealt in a lot of ways with some of that anger and frustration, and the things she needs to." "She doesn't view herself as brain-injured or disabled enough to be lumped in with 'those people.' She's real typical in that way. She wants to be viewed as normal."

"We make our son participate [in special activities], even though he says 'I'm not one of those people. I'm not mentally handicapped.' He doesn't always know he has a brain injury, and has not reached the point where he will admit that he has a brain injury. At times he can acknowledge it for a short time but he hasn't accepted it."

"I don't know what it takes him to accept [pause] what's happened, but he doesn't have a lot of time for meeting with people who – because then it's meeting new people and he doesn't like that ... he stays away from [support groups] and stuff ..."

Finding strength. In this study, even those caregivers who had ceased to provide care their own home remained very involved in supporting and caring for their injured family member. Their narratives, combined with those of the other caregivers, revealed many strengths that enabled them to continue being a caregiver, and suggested sources of their continued strength.

All of the caregivers in this study were able to identify personal characteristics within themselves that had enabled them to deal with the challenges of being a caregiver over the long term. Many used words such as "strong" and "tough" to describe themselves.

"I says [to my children], 'No. You gotta be strong like me. I got a strong mind and I got a strong heart,' I says. When I think of something, nothing ever gets in the way. I'll go do it."

A number of other qualities, such as a sense of humour, empathy, a positive attitude, the ability to live with the unknown, and the ability to make difficult decisions also spoke to the caregivers' strength of character. One of the more consistently mentioned characteristics was "patience."

"It's hard, but I think the main thing you need is a double dose or a triple dose of patience ... You've got to learn to let go all over again. You know, you did it once already, but you didn't plan on doing it at his [survivor's] age and my age."

"It could be almost, like, frustrating if you're not patient, because you could get snappy with her, sort of thing ... you have to stop and think that that person really doesn't get it,

so you <u>have</u> to be patient. If you're not, then you're not the right kind of person to be a caregiver."

"... you have to be extremely patient. I think the hardest part is the understanding, because after a while, it's <u>so</u> repetitious, and it's exhausting ... It's a good feeling when you can accomplish that, when you can really learn to be patient in the true sense of the word."

Some caregivers acquired their strength and self-confidence in childhood or through previous caregiving experiences. Others gained confidence and validation through feedback from family members and professionals.

"My father was a very positive person ...He taught us as kids that it didn't matter what happened in life, you could handle it. Sort of acceptance of change, and that."

"... I was a caregiver from way before, so somebody that can't do nothing for themselves, I know how to look after them, I guess."

"When [my son] was injured, one of my children said to me, 'I always knew that you were the tough one.' The doctors also thought that I was strong, too and said so."

Many of the same qualities that enabled caregivers to find peace of mind, also helped to keep them strong.

"My prayers [keep me strong]. Tell you the truth, my prayers. The Creator give me the strength. He put me on trial, that's why He gave me this kind of life. So I took it. Instead of giving it up, I took it..."

Caregivers also found strength in their relationships with others. In this study all but one caregiver were married. For parent caregivers, spousal support was mentioned as an important source of strength.

"And you've got to have a pretty good, pretty solid marriage before. Like, [my spouse] and I work together on just about everything."

"I think my husband's been very supportive. I couldn't have done it without him. There were many times that I think [Survivor] and I would have probably killed each other!"

For spouse caregivers, other family members were a very important source of renewal and support.

"When things are going good, that's when I [pause] I forget those bad times, and I just live for these really good times, when they are good. That's the only way I can do it, because otherwise, I would be run out ... I guess it's just that I love it when the kids are with [my husband] and I. My kids are so much fun! ... If I can make my kids laugh, just by something silly that I say, then — oh! that's just —! wonderful!"

"...my mother, when she became older and sick, I moved her here ... and she was in the nursing home. She got so low the last year or so that she couldn't talk. She couldn't talk, she could hardly even feed herself. But she was great. She was a great listener, because I could sit and tell her anything. I used to, you know!"

Another very important sign of strength exhibited by caregivers was their ability to celebrate every success, even the very small ones.

"I remember back the first time that we had any response out of her at all was to — [my wife] was out shopping — I was changing her Depends ...she had this big wide grin on her face and all teeth, and she had never done that before. She'd never been able to do

that.   So [my spouse] walked in just after ... I was yelling, 'Get in here, look at this!' I was euphoric. This is like someone just gave me a million dollars. I'm serious. It was a first step. That, in itself, was worth it."

[About survivor learning to turn the page of a magazine] "That simple thing was a huge step. Every step is a huge step, but they can be very, very slight. In your eyes, it's major, in [our son]'s eyes, it's major, but to somebody else, you turned a page — what's the big deal? You gotta be there before you can understand that, I guess."

When asked what advice they had for other caregivers, respondents frequently spoke of the importance of being able to talk to others who understand brain injury and have been through the experience themselves.

"When you're in a hospital and you look at a person in intensive care, the things that go through your head are just unreal. You can't fathom it unless you've been through it ... There is no way that you can get your head straight. If there would have been somebody we could have sat down and said okay, there's what's happened, there's a real success story, and this is what we did ... if you had some insight or just a little bit of [pause] camaraderie —"

"As far as bringing them home, there is one thing I would pass on to people: to grab all the help you can get at, because we never did ... We thought, no, we don't need anybody ... This is our son. It's up to us to get through this. And that's not right. You need backup, you need help. Even talking to people about how they went through it is a big thing, because people that haven't been through it'll never understand."

Information about community resources was also mentioned.

"I think my initial advice would be to make sure that you find out about every possible resource you might need before you get them home. There are a lot of community

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resources out there, but if you don't know about them, you often just don't have the energy to be the one to try to find out. It's often, just [pause] you have as much [pause] your energy is drained by looking after this person. And the emotional stress around the fact that your son or daughter is now brain injured. Coming to grips with the fact that they won't be the same, ever again. So you really don't [pause] I don't think you should be expected to have to find out about resources or go along and have resources there that you don't know about. So my advice is to make sure that you find out, even though, maybe the health care providers don't think you might need them, you should still get the information and know how to access them."

Another caregiver highlighted the lack of funding for adults with brain injury and the lack of appropriate housing.

"What's been happening in the last month is we have found funding for [our son] to live in his own home with 24-hour care. We had to fight very hard to get that funding, because currently in the system, there is no funding for people with brain injury, for adults over the age of 18 with brain injury." "We went to see the group home the region wanted to put our son in. It was in terrible shape and was in a bad part of town right across from a seedy hotel. I said, 'If [our son] stays here he's going to get beat up and get into trouble.' I was told, 'No, you don't have to worry. We have two strong body guards at the door - they'll control him.' I said, 'No, I'm sorry, that's not the way you control [my son].' ... They [the system] have to stop warehousing people."

Summary

This chapter presented data that describes caregivers' decisions to bring their injured family member home, and their experiences as caregivers over the long-term. Feeling discouraged by the lack of alternatives, believing that they could provide a better environment for recovery, and feeling under pressure from the survivor all contributed to the decision to provide care at home. Survivor longing had a particular influence on the timing of the return home. Because of this, and because of other differences in the

survivors' rates of recovery, caregivers in this study had to deal with different kinds and levels of disability when their family member first returned home.

Regardless of their different 'starting points' caregivers all went through a similar process of rebuilding. After an average of four years of caregiving in their own home, respondents consistently described a process of adjustment, goal-setting, and setting personal boundaries in order to 'have a life.'

Caregivers spoke of two types of adjustment: adjustment to the loss of their (and the survivor's) previous life, and adjustment to the responsibility of caring for an adult with brain injury.

Recovery was a key goal of caregivers who saw themselves playing the role of teacher, coach, and advocate as they assisted their injured family member to regain important life skills. Social skills were particularly important. Caregivers also expressed concern about their family member's future. Most felt that independence was possible and necessary, but few expressed concrete plans to reach that milestone. The experiences of three caregivers, whose injured family members had recently moved out on their own, suggests that there is no one definition of independence – that outcomes depend on many dynamics, including the survivor's abilities and, moreover, what the caregiver can and is willing to go through to facilitate that process.

Caregivers spoke about the need to have time and space away from the survivor. Through various means they were able to find time to begin having a life of their own again, and experience some peace of mind knowing the survivor was not completely dependent on them. A connection with God, nature, or other people enabled caregivers to find time, space, and peace of mind.

Rebuilding presented many challenges and required great strength on the part of caregivers. Survivors sometimes resisted caregivers' efforts. Survivors' anger and repeated set-backs often frustrated caregivers' attempts to continue supporting recovery and independence. Frustration was taking a slow toll on some caregivers and had resulted in an urgent need to change the caregiving arrangement in two cases. Patience, confidence, spousal and family support, and the ability to celebrate small successes were the more frequently mentioned sources of strength.

When asked what advice they had for other caregivers, respondents recommended that people use more of the services that they never used. The need for an improved system of care and housing were the underlying messages in some caregivers' comments.

The following chapter discusses, in detail, the strengths and limitations of these findings and their implications for policies and practices that impact on caregivers of adults with brain injury. The chapter will include references to literature on the topics of caregiver well-being, resilience, the caregiving experience, and systems of care to determine if these findings are an accurate picture of caregiving and what new information they many contribute. The chapter will conclude by offering recommendations that could assist individuals in realizing more success and less uncertainty following the injury of a family member.

This study applied a qualitative research approach, outside of the clinical setting, to gather information on the experiences of a particular group of caregivers who are typically overlooked — those who are "faring well" in their caregiving role. Their words convey important information about the caregiving experience, answering key questions about the personal and environmental factors that influence the course of caregiving. Findings add to the current literature on TBI caregiving which traditionally has focused on the pathological aspects of caring and devising new clinical and rehabilitative practices to assist individuals in dealing with their problems.

While the data could have been sorted in several ways to answer several different questions, the arrangement which best fit the data and answered questions about the caregiving experience as a whole was one which portrayed two major transitions: coming home; and rebuilding. These categories, and their sub-categories are displayed in Figure 5-1 below. A certain level of generalizability is supported by the similarity of these findings to those of other researchers.

Figure 5-1: Thematic groupings for interview data

First level	Second level	Third level
Coming Home	Familial Responsibility	
	Lack of Alternatives	
	Survivor Longing	
Rebuilding	Adjusting	Adjusting to Loss
		Adjusting to New Responsibilities
	Setting Goals	Setting Goals for Recovery
		Setting Goals for Independence
	Setting Personal Boundaries	Finding Time and Space
		Finding Peace of Mind
	Staying Strong	Challenges to Staying Strong
		Finding Strength

Discussion of findings: Coming home

   The role of familial responsibility. In reviewing the circumstances surrounding the decision to bring the survivor home, it was clear that each caregiver in this study held a firm belief in the concept of family helping family. This value was depicted in other ways aside from the caregiving relationship, such as the caregivers' involvement in providing care for grandchildren or aging parents. Others displayed the caring principle in their work or through strong ties with a religious community. For spouse caregivers, responsibility was taken to be part of the marriage commitment, as well as a sign of their commitment to keeping family together. They, along with the other caregivers who participated in this study were clearly influenced by the large investment (emotional and otherwise) they had in their relationship with the survivor and they wished for some part of that relationship to continue. This was supported by the actions of those caregivers who had physically separated from the survivor but who maintained a high degree of involvement in providing care and support. Their statements reflected their belief that they would always be involved.

   Lack of alternatives.   A lack of acceptable care alternatives and negative experiences with "the system" may well have been a contributing factor to some caregivers' strong beliefs that the home was the best healing place, and family the best care providers. Not all were as accepting of the concept of home and family as the best path to recovery, with some citing the difficulties that family relatedness created. Some stated real reservations about having the survivor return to their home after rehabilitation.

   Survivor longing. Survivor longing was often presented as the decisive factor in the survivor's coming home. The consistency and intensity with which this factor was presented was unexpected and was not dealt with in any of the literature on the topic of brain injury or caregiving. Still, its impact on caregivers' decision-making was profound. It affected their decision to bring their injured family member home, when that transition would take place and in some cases, their perception of the survivor's well-being upon returning. It also influenced the type of responsibilities and challenges they would face, with some needing to arrange various therapies and home care in their community.

<u>Comparisons with other literature</u>

Factors influencing the choice to provide care in one's own home is under-investigated (Farran, 1997), however some researchers have commented on values similar to those found in this study, that shape the caregiving experience. Most of these studies focus on female caregivers. In a grounded theory based study of family caregiving at home, Boland and Sims (1996) found that a commitment to care and a belief in home as a healing place both served to moderate burden. Belief in home as a healing place "was the primary reason for engaging in home care" (p. 56). Home was described as a beneficial environment where the care recipient would recover faster and feel better. Similar to the survivors' longing to be home that was present in this study, caregiver respondents in Boland's and Sim's study remarked that the care recipient did not like being in hospital, wanted to be home, and was more hopeful and positive when at home.

Guerriere and McKeever (1997) studied the experiences of mothers of young children who had survived brain injury and found that all the mothers seemed to share "society's conception of the 'good' mother role, which includes the belief that they are responsible for the well-being of children" (p. 112). This belief was tied to feelings of guilt when they failed at their attempts to make their children better.

Carson (1993) developed a theory describing parents' experiences following the return of their adult child with brain injury to the home setting. Investigation focused on both parents' experiences after their injured child had come into their home. Carson found that mothers typically maintained "rescaled priorities" (p. 169) — characterized by putting the survivor's needs first — for a longer period than fathers whose earlier return to work brought about a new order of priorities.

The most detailed discussion of the ideals underlying caregiving is provided by J. Wuest (1996) who undertook a grounded theory study to investigate the environmental influences on women's caring. She describes four primary environmental conditions which influence the caregiving process: caring ideals; caring proximity; caring options; and caring rewards. The predominant caring ideal was that "caring is what life is" and is "fundamentally good" (p. 51). Caring proximity influenced caregiving in the geographic, relational, and cultural sense. Wuest noted that for many women love was a significant

underlying factor that influenced their caring experience in both positive and negative ways. Women's need for "connectedness" also varied, with some desiring connections primarily with their nuclear family, and others maintaining vast connections with the community. These differing perspectives, also evident in the present study, influence what supports will be sought and utilized by caregivers.

Limits on the availability and suitability of caring options were problematic for caregivers. Wuest (1996) draws the connection between caring options and the larger domain of community caring ideals which influence the number and type of resources available. Caring rewards have a sustaining impact on female caregivers — something which was evidenced in this study under the experiences related to "Rebuilding."

Toward an explanation of the "Coming Home" experience

From this review of the findings and associated literature it is clear that the decision to provide care to an adult family member with a brain injury is influenced by cultural and social imperatives. Cultural norms and ideals around family caring, particularly by females, are reflected in caregivers' sense of responsibility for the well-being of their family member. These personal beliefs are reinforced by a lack of appropriate care alternatives. Further, brain injury places a unique biological imperative upon caregivers who must find ways to respond to the demands of a family member who lacks the cognitive capacity to reason or control their emotional response to being hospitalized. Whether it is best for the recovery of the survivor or not, family assumes the "default position" (DeJong, Batavia, and Williams, 1990) for both the survivor who is unable, at that point, to care for himself/herself, and society which has not developed the resources to respond to the needs of brain injured adults.

Discussion of findings: Rebuilding

The caregivers involved in this study were not in a position of passive maintenance, but were actively involved in assisting their family member in learning important skills required for integration into the community. After a period of adjusting to their new responsibilities, caregivers began the work required to meet the goals that had

been set for the survivor's further recovery and independence. Goals were also set with regard to caregivers' needs to "have a life." This goal was sought through setting personal boundaries and various means that helped them to stay strong in the face of challenges and set-backs.

Adjusting. Adjustment was described retrospectively by caregivers. Looking back, they were able to recall both positive and negative changes that took place. The dominant negative changes were those that caused difficulties in their relationship with the survivor and others, such as having to deal with the survivor's outbursts, conflicts with family members over care, a lack of time to maintain friendships and participate in hobbies, and the survivor's heavy reliance on them to provide social and recreational opportunities. In conjunction with their new set of caregiving responsibilities, the period of adjustment really constituted a process of redefining their relationship with their injured family member. Lezak (1988) describes the process as follows:

> Families who make the transition to more appropriate relationships with the brain-damaged patient must go through the painful process of relinquishing old habits of thinking about and dealing with the person the patient was while developing new percepts and reaction patterns that are almost inevitably less flattering, less pleasurable, and less hopeful. (p. 123).

Setting goals for recovery and independence. The goals and expectations of caregivers regarding survivor recovery and independence is one area that is gaining more attention in research due to the shift in social values toward the integration of people with disabilities in the community. Caregivers' recovery expectations are often assessed in relation to their congruity with more 'realistic' medically-based prognoses. Springer, Farmer and Bouman (1997) address common misconceptions about traumatic brain injury that surface early after the injury. Beliefs that a full recovery is possible, misconceptions about the amount of time recovery will take, and limited understanding of the cognitive outcomes of TBI are related to caregiver disappointment, unrealistic demands on the survivor, caregiver - survivor conflict, and failure to take appropriate actions.

Unfortunately the authors do not return to explore their earlier statement that some misconceptions are related to optimistic appraisal strategies that help people cope.

Davis and Grant (1994) investigated the processes caregivers used in constructing the reality of recovery. Their findings suggest that the focus on recovery represents caregivers' "own tentative first steps toward regaining control and seeking normalcy in their life and the life of their families" (p. 74) and that it assists caregivers in feeling rewarded for, and finding meaning in, their caregiving efforts.

Given caregivers' strong reaction toward negative appraisals given by health professionals in this study and others (Smith, 1998), it would seem crucial to understand more fully the role that recovery expectations play in sustaining hope.

In this study, caregivers related information that showed how their recovery expectations evolved over time. Interestingly, several conveyed that it was a challenge to deal with the increasing capabilities of their injured family member. Seeing improvements slowly added to their ability to envision an independent life for the survivor while repeated set-backs appeared to create real uncertainty around the likelihood of independence.

While there is evidence that brain injury survivors and caregivers alike desire independence (Brzuzy & Corrigan, 1996; Brzuzy & Speziale, 1997; Carson, 1993; Howden, 1992; Smith, 1998; and Willer, Allen, Durnan & Ferry, 1990), little has been written about the factors that motivate this goal. Brzuzy and Speziale suggest that it is part of the goal to "reestablish, as much as possible, normal individual and family life cycle trajectories" (p.86). In other studies (Howden, 1992; Smith, 1998), and in this one, concerns for the future well-being of the survivor seem to play the key motivating role.

In this study, survivor independence was synonymous with two things: the long term well-being of the survivor and the long-term well-being of the caregiver. For those who were continuing to live with their injured family member, particularly adult children, the primary concern was that the survivor's needs would not be looked after if they were no longer there. The three caregivers who had already made the transition (for better or worse) from care in the home to care outside the home, were more apt to describe the impact that the change had on their own well-being.

Fear of the future was the biggest driving force toward independence, though other research would suggest that survivor desire for freedom also plays a role (Brzuzy & Corrigan, 1996; Willer et al., 1990). In a study conducted for the Northern Alberta Brain Injury Society (Howden, 1992) family members identified long-term planning to enable the person with the brain injury to be as independent as possible to be a significant issue. At the same time, nearly one-third reported that it was difficult or impossible for them to plan for the future at all. In Smith's (1998) study, caregivers reported feeling completely unsupported in their efforts to arrange care, either for the short or long term, for their injured family members.

The findings in this study suggest that a number of other factors influence caregivers' plans for the survivor's future independence. These include: personal fears and anxieties, prior experiences with the acute care and rehabilitation system, and limited perceptions about the meaning of "independence."

Anxiety and stress accompany any major life change. Given the major changes that caregivers have already gone through, it is understandable that some would not desire to disrupt what is a relatively stable (though fragile) arrangement. Many caregivers expressed the opinion that family care was separate from care in "the system," or that they were working against the system to achieve what was best for the survivor. Past experiences in which the family was shut out of major decisions by health professionals no doubt served to create or reinforce these values. Caregivers also seemed to hold different views about what degree of functioning was required in order for the survivor to live independently. One caregiver equated independence with the need for the survivor to have control over his own finances. Only one caregiver expressed the belief that 24-hour paid care and independence could co-exist, providing that the type of residential environment and the staff providing the care were respectful of the caregivers' autonomy.

Setting personal boundaries. By setting mental and physical boundaries on their caregiving responsibilities, caregivers in this study were able to regain a sense that they once again had a life. Through the actions that they took, it appeared that having a life was strongly related to rebuilding health connections in the world — healthy connections with the survivor, with other people, and with oneself. The key message seemed to be

that being an involved, effective caregiver should not require one to sacrifice 100% of him/herself. In the words of one respondent: "If you don't have a life of your own, I don't know how you could do it."

The process of setting boundaries is also identified by Wuest (1997) and Lezak (1986). Lezak describes it as emotionally and physically disengaging from the injury survivor and describes the benefits as follows:

> Emotional detachment may free caretakers form debilitating anger, guilt or concern about propriety, and allow the family to rebuild a meaningful life. Family members may not experience a change in what they do so much as a reorientation that can give them some peace and emotional liberation." (p. 247)

In a process Wuest (1997) calls "precarious ordering," caregivers move from a reactive stage characterized by disorder, to a more ordered stage in which they act proactively to set limits on the nature and intensity of caring demands.

Staying strong. In this study, personal, relational, and environmental factors were all mentioned in relation to the process of staying strong. Survivors' behavioural issues and caregivers' waning energy were the most consistently mentioned challenges, as were a lack of information, support and resources. Surprisingly, most mentioned personal strength as being central to their ability to carry on the caregiving role. In addition, the strength of the survivor and other family members was consistently implied and appeared also to have a bolstering affect on the caregiver's continued efforts.

Toward an explanation of the process of rebuilding

The entire rebuilding process was shaped by and made possible through caregivers' tremendous resilience. Resilience is typically described as a quality that enables people to rebound from adversity. It has been more specifically defined as "a global term describing a process whereby people bounce back from adversity and go on with their lives" (Dyer & McGuinness, 1996). Dyer and McGuinness identify the following "critical attributes" (p.277) of resilience:

- rebounding and carrying on toward a direction of life

- having a sense of self-esteem and a path in life

- determination and perseverance until a goal is achieved

- a prosocial attitude and behaviours that encourage attachment to others who can assist a person in achieving her/his goals

The underlying theme in all of these attributes is an ability to set and achieve goals. This ability was very apparent in all of the caregivers who participated in this study. Goals were set in regards to survivors' recovery and independence, as well as caregivers' own satisfaction and well-being. It is crucial, when considering the findings, to retain the distinction between caregivers' goals in both areas. While it is safe to conclude that caregivers' resilience and well-being enabled them to continue providing care over the long-term, there was no indication in this study that the goals regarding their personal well-being were undertaken for this purpose. Rather, they associated their efforts with their own personal need to "have a life" in spite of the challenges and responsibilities brought on by their caregiving role.

Conclusions and recommendations

The focus of this study has been to apply a qualitative approach within a strengths-based ecological theoretical framework to attain a better understanding of the caregiving experience. In particular, it set out to answer three questions: what personal characteristics of caregivers influence their ability to provide care over the long-term; what environmental factors influence their ability to provide care over the long-term; and how do the two domains interact to shape caregiving experiences? Answers to these questions challenge key assumptions in policy and clinical/rehabilitation practice such as: focusing on the individual for solutions to stress; assuming that it is desirable to prolong family caregiving as long as possible; and placing insufficient emphasis on the desires and abilities of survivors and caregivers to direct the reintegration process.

Revisiting the research questions

Readers expecting this study to result in a discrete set of personal and environmental factors impacting on the caregiving experience will be disappointed that the

findings do not yield this kind of information. What this study does accomplish is to provide a portrait of caregivers and their circumstances and how the two interact.

The most important observation regarding the personal characteristics of the caregivers who participated in this study relates to the way they define themselves and their caregiving role. All respondents were intelligent, resourceful, and highly driven individuals — in a word, resilient. They did not see their role as one of long-term maintenance but of planning and assisting their injured family member to achieve important life goals. For the majority, this meant achieving a level of independence and self-sufficiency. The goals associated with spousal survivors are somewhat different, with caregivers showing more concern that their family member be able to exercise an appropriate level of control and carry out their role as parent satisfactorily.

An equally significant goal expressed by study participants was to regain their own independence from the constraints of caregiving. In many ways, the caregiving arrangement was contradictory to their ability to achieve the physical and mental space required to feel like they had a life of their own.

The most significant observation with regard to the environmental factors influencing the caregiving arrangement emerged through caregivers' descriptions of their conflicts and negative experiences with "the system" and society. Negative appraisals from medical professionals, difficulties accessing appropriate resources in the community, discouraging feedback from friends and a general feeling of isolation expressed by caregivers points to a serious disjuncture between their ideals and those of the society at large. The most apparent result of this disjuncture is uncertainty and fear among caregivers about the future. They are not alone in their uncertainty — other family members, including the injury survivor share the same fears.

Fine (1991) notes that "the most stressful dimensions [of extreme life events] appear to be those that challenge personal assumptions about oneself and the structure of the world one lives in" (p.495). Study participants' narratives clearly show how traumatic brain injury turns life upside down. This study suggests that the lack of support they receive in "righting things" is a source of continuing trauma. It is also a very likely cause of what Brzuzy and Speziale (1997) identify as the pervasive, long-term stress experienced

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by families of people with brain injury. Their comments suggest that ways to alleviate this stress are as important as dealing with the type of intermittent crises that more often bring individuals into contact with the formal care system.

A final, and very key finding is that regardless of the personal and environmental resources available to caregivers, doing it forever is not an option. Only one caregiver in the present study acknowledged this outright. Other caregivers, in particular parent caregivers, acknowledged it through their worries that their family member may not be adequately prepared for life when they are no longer there to support them.

Each interview, though unique in many ways, gave an overall impression of the fragility of the caregiving arrangement and conveyed the sense that major change could happen suddenly and with unpredictable results. Fine (1991) reminds us that even the most resilient individuals can experience vulnerability; that resilience that enables people to rebound from extremely stressful situations can slowly erode over the long-term, but that there is more to be learned about how and why this occurs.

Tamm (1999) cautions that we should consider the potential for human resilience and adaptability to put people into an "undesirable situation" (p.54). Quoting French medical historian René Dubos, "this very adaptability enables them [human beings] to become adjusted to conditions and habits which will eventually destroy the values most characteristic to human life" (as cited in Tamm, p. 54). The recognition that caregiving can be meaningful and yield positive rewards, yet still create difficulties (Wuest, 1997), and that the demands and expectations placed on caregivers are incongruent with their own need for autonomy should strengthen our resolve to more carefully examine the role of family as caregiver and where the current situation may lead in the future if not adequately addressed.

Summary

The following table illustrates key aspects of the disjuncture between caregivers' expectations regarding their role and society's expectations as reflected in social policy and institutional practice. Caregiver expectations are derived from an interpretation of the

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study findings. Societal expectations are based on the author's interpretation of caregivers' reported experiences and the current literature.

Figure 5-2: Caregiver expectations and societal expectations regarding the caregiving role

Caregivers

- Caregiving means facilitating survivor's recovery and independence
- Caregiving is inherently stressful and unpredictable
- Survivor is a unique individual with unique needs and desires
- Worried about the long-term

- I have to have hope
- Caregiving shouldn't require me to give up my life
- No-one can do it forever

Society

- Caregiving is a maintenance role; family assumes default position
- Stress can be avoided and treated

- Little room for flexibility

- Concerned with relatively short-term outcomes
- You have to be realistic
- It's all in how you perceive it

- The longer the better

Implications and recommendations

Several researchers have already begun to ask questions about the roles of individual, family, community, and society at large in supporting positive outcomes for brain injury survivors, and how those outcomes ought to be defined (Brzuzy & Corrigan, 1996; DeJong, Batavia & Williams, 1990; Horn, 1992; Roberts, 1993; Willer, Button and Rempel, 1999). There is growing agreement amongst researchers and practitioners in the sphere of community-based service delivery that evaluation must indicate the impact that programs have on client outcomes (United Way of America, 1999). These efforts should continue, with a focus on ensuring that outcomes are client-defined.

Further, institutions and legislative bodies must recognize their responsibility for assisting families and survivors in achieving long-term outcomes. This concept is embodied in DeJong, Batavia, and Williams' (1990) model of a "continuum of responsibility" (p.16) in which the individual and family are most closely and directly responsible for outcomes, followed by community agencies involved in direct interventions, followed by social bodies that are more indirectly involved, but no less responsible for long-term outcomes. The social sphere in particular, has a role to play in

building a strong community sector, which in turn strengthens and augments the efforts of families and individuals (DeJong, et al., 1990).

Researchers and program managers have a responsibility to further develop theoretically sound and practical methods for measuring client-defined outcomes. For those using these tools, there is a responsibility to learn to present their findings in a way that communicates their importance to funders at all levels, including government. It follows that funding bodies have a responsibility to begin judging the relevance of programs based on client impact rather than cost-efficiency. More research must be conducted that meets these re-defined information needs at the policy-level. One suggestion would be to investigate the transition experiences of caregivers and survivors who have gone on to independence after living in the family home. Knowledge about how to conduct relevant research and communicate findings to policy makers must be developed (Frankish, n.d.).

A commitment to measuring client-focused outcomes implies a commitment to use the results to improve efforts at all levels (whether at the clinical level, community service level, or policy level) to optimize those outcomes. This study suggests that there are many issues at the larger social and policy level that currently impact on caregivers of adults with brain injuries. These must be clearly identified and addressed.

All of this must be done with a clear understanding of the experiences of caregivers and adults with brain injury. Misconceptions regarding the desired goals of caregivers only serve to exacerbate their problems and wear down their resilience.

A further misconception is that formal supports are a replacement for family care. Cantor (1989) cites information which suggests that "the provision of a range of community interventions ... does not reduce the involvement of family but encourages the continuation of their efforts" (p. 111). Information provided by Willer, Button and Rempel (1999) suggests that, under certain circumstances, home and family have a role to play in facilitating the successful long-term integration of brain injury survivors into the community.

Results of this study highlighted one such group of caregivers who appeared to have the capacity and desire to fulfill this role. It must be recognized, however, that this is

a specialized population, and there are likely to be many more families who are not in such a position.

   While the issue of family responsibility for care must always be approached cautiously, this study shows that some families wish to be involved in care, provided their efforts are rewarded. That the society, through its policies, institutional practices, and expectations works against their goals to increase the independence and self-sufficiency of their injured family members, seems a sad waste of human potential.

Abel, E. K. (1990). Informal care for the disabled elderly. Research on Aging, 12(2), 139-157.

Alberta Centre for Injury Control and Research. (1999). Head injury facts. Edmonton, AB: author.

Alberta Centre for Injury Control and Research. (2000). An action plan for the Alberta Centre for Injury Control and Research in the area of community rehabilitation. Edmonton, AB: author.

Alberta Centre for Injury Control and Research. (2001a). [Head injuries: Inpatient hospitalizations, Albertans, 1997]. Unpublished raw data.

Alberta Centre for Injury Control and Research. (2001b). Neurotrauma data report: Head injury and spinal cord injury, 1997. Edmonton, AB: Author.

Barer, B. M., & Johnson, C. L. (1990). A critique of the caregiving literature. The Gerontologist, 30(1), 26-29.

Beals, M. P., Mathews, R. M., Elkins, S. R., & Jacobs, H. E. (1990). Locating community resources for lifelong living. Journal of Head Trauma Rehabilitation, 5(1), 31-39.

Berg-Weger, M., & Tebb, S. S. (1998). Caregiver well-being: A strengths-based case management approach. Journal of Case Management, 7(2), 67-73.

Boland, D. L., & Sims, S. L. (1996). Family care at home as a solitary journey. Journal of Nursing Scholarship, 28(1), 55-58.

Brain Injury Association of the United States of America. (n.d.). The costs and causes of traumatic brain injury. Alexandria, VA: Author. Retrieved February 5, 1998, from the World Wide Web: http://www.biausa.org/costsand.htm

Brain Injury Rehabilitation Program. (1998). [Discharge data]. Unpublished raw data.

Brain Injury Rehabilitation Program. (n.d.). Admission / discharge medical rating scale. Ponoka, AB: Author.

Brain Injury Rehabilitation Program. (n.d.). An introduction to the Brain Injury Rehabilitation Program at Ponoka, Alberta [Brochure]. Ponoka, AB: Author.

Britten, N. (1996). Qualitative interviews in medical research. In N. Mays & C. Pope (Eds.), <u>Qualitative research in health care</u> (pp. 28-35). London: BMJ Publishing Group.

Brooks, D. N., & McKinlay, W. (1983). Personality and behavioural change after severe blunt head injury — a relative's view. <u>Journal of Neurology, Neurosurgery, and Psychiatry, 46,</u> 336-344.

Brzuzy, D. L., & Corrigan, J. D. (1996). Predictors of living independently after moderate to severe traumatic brain injury: A comparison study. <u>Journal of Head Trauma Rehabilitation, 1996, 11</u>(3), 74-83.

Brzuzy, S., & Speziale, B. A. (1997). Persons with traumatic brain injuries and their families: Living arrangements and well-being post injury. <u>Social Work in Health Care, 26</u>(1), 77-88.

Cantor, M. H. (1989). Social care: Family and community support systems. <u>The Annals of the American Academy of Political & Social Science, 503,</u> 99-112.

Carson, P. (1993). Investing in the comeback: Parent's experience following traumatic brain injury. <u>Journal of Neuroscience Nursing, 25</u>(3), 165-173.

Cowen, E. L. (1991). In pursuit of wellness. <u>American Psychologist, 46</u>(4), 404-408.

Davis, L. L., & Grant, J. S. (1994). Constructing the reality of recovery: Family home care management strategies. <u>Advances in Nursing Science, 17</u>(2), 66-76.

Deis, K., Simpson, J., & Jumaga, D. (1997). <u>Strengths and capacities of caregivers in Barrhead: Report of survey results.</u> (Available from Aspen Regional Health Authority #11, Provincial Building, 10003 - 100 Street, Westlock, Alberta, Canada, T7P 2E8)

DeJong, G., Batavia, A. I., & Williams, J. M. (1990). Who is responsible for the lifelong well-being of a person with a head injury? <u>Journal of Head Trauma Rehabilitation, 5</u>(1), 9-22.

Dubos, R. (1965). <u>Man adapting.</u> New Haven: Yale University Press.

Dyer, J. G., & McGuinness, T. M. (1996). Resilience: Analysis of the concept. <u>Archives of Psychiatric Nursing, 10</u>(5), 276-282.

Farran, C. J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress/adaptation and existentialism. <u>The Gerontologist, 37</u>(2), 250-256.

Fine, S. B. (1991). Resilience and human adaptability: Who rises above adversity? The American Journal of Occupational Therapy, 45(6), 493-503.

Frankish, C. J. (n.d.). Speaking in tongues: Lessons for communication among health researchers, practitioners and policy makers. Presentation at the meeting of the Alberta Public Health Association, Edmonton, AB.

Glenrose Rehabilitation Hospital. (n.d.). Brain injury: coping with the results of brain injury. Edmonton: Capital Health, Glenrose Rehabilitation Hospital.

Green, L. W., Richard, L., & Potvin, L. (1996). Ecological foundations of health promotion. American Journal of Health Promotion, 10(4), 270-281.

Guerriere, D. & McKeever, P. (1997). Mothering children who survive brain injuries: Playing the hand you're dealt. Journal of the Society of Pediatric Nurses, 2(3), 105-115.

Hanneman, R., & Blacher, J. (1998). Predicting placement in families who have children with severe handicaps: A longitudinal analysis. American Journal on Mental Retardation, 102(4), 392-408.

Heinemann, A. W., & Whiteneck, G. G. (1995). Relationships among impairment, disability, handicap, and life satisfaction in persons with traumatic brain injury. Journal of Head Trauma Rehabilitation, 10(4), 54-63.

Horn, L. J. (1992). Systems of care for the person with traumatic brain injury. Physical Medicine & Rehabilitation Clinics of North America, 3(2), 475-492.

Howden, L. (1992). Report on survey results for family support project. Edmonton, AB: Junior League of Edmonton and Northern Alberta Brain Injury Society.

Jacobs, H. E. (1988). The Los Angeles head injury survey: Procedure and initial findings. Archives of Physical Medicine and Rehabilitation, 69, 425-431.

Jacobs, H. E., Blatnick, M., & Sandhorst, J. V. (1990). What is lifelong living, and how does it relate to quality of life? Journal of Head Trauma Rehabilitation, 5(1), 1-8.

Kane, R. A., & Penrod, J. D. (1995). Family caregiving in an aging society: Policy perspectives. Thousand Oaks, CA: Sage.

Kisthard, W. E., & Rapp, C. A. (1992). Bridging the gap between principles and practice: Implementing a strengths perspective in case management. In Rose, S. M. (Ed.), Case management and social work practice (pp. 112-125). New York: Longman Publishing Group.

Kramer, B. J., (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. The Gerontologist, 37(2), 239-249.

Kramer, B. J., (1997). Gain in the caregiving experience: Where are we? What next? The Gerontologist, 37(2), 218-232.

Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. Brain Injury, 8(3), 211-230.

Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994). Primary caregivers' psychological status and family functioning after traumatic brain injury. Brain Injury, 8(3), 197-210.

Lezak, M. D. (1986). Psychological implications of traumatic brain damage for the patient's family. Rehabilitation Psychology, 31(4), 241-250.

Lezak, M. D. (1988). Brain damage is a family affair. Journal of Clinical and Experimental Neuropsychology, 10(1), 111-123.

Marshall, C., & Rossman, G. B. (1995). Designing qualitative research (2nd ed.). Thousand Oaks, CA: SAGE Publications, Inc.

Mathewson, M. (1997). Courage after coma: A family's journey. Edmonton, AB: Uneek Experience.

Mays, N., & Pope, C. (1996). Rigour and qualitative research. In N. Mays & C. Pope (Eds.), Qualitative research in health care (pp. 10-27). London: BMJ Publishing Group.

Miller, B., & Lawton, P. (1997). Introduction: Finding a balance in caregiver research. The Gerontologist, 37(2), 216-217.

Morse, J. M., & Field, P. A. (1995). Qualitative research methods for health professionals (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Morton, M. V., & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: A literature review and recommendations. Brain Injury, 1995, 9(1), 81-92.

Moscato, B. S., Trevisan, M., & Willer, B. S. (1994). The prevalence of brain injury and co-occurring disabilities in a national household survey of adults. Journal of Neuropsychiatry and Clinical Neurosciences, 6(2), 134-142.

Neufeld, A., & Harrison, M. J. (1995). Reciprocity and social support in caregivers' relationships: Variations and consequences. Qualitative Health Research, 5(3), 348-365.

Noonan, A. E., & Tennstedt, S. L. (1997). Meaning in caregiving and its contribution to caregiver well-being. The Gerontologist, 37(6), 785-794.

Osborn, C. L. (1998). Over my head: A doctor's own story of head injury from the inside looking out. Kansas City: Andrews McMeel Publishing.

Panting, A., & Merry, P.H. (1972). The long-term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. Rehabilitation, 38, 33-37.

Patton, M. Q. (1990). Qualitative evaluation and research methods (2nd ed.). Newbury Park, CA: Sage Publications.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30(5), 583-594.

Perlesz, A., Kinsella, G., & Crowe, S. (1999). Impact of traumatic brain injury on the family: A critical review. Rehabilitation Psychology, 44(1), 6-35.

Rapp, C. A. (1994). Theory, principle, and methods of the strengths model of case management. In M. Harris & H. Bergman (Eds.), Case management: Theory and practice. Washington, DC: American Psychiatric Association.

Rapp, C. A., & Wintersteen, R. (1989). The strengths model of case management: Results from twelve demonstrations. Psychosocial Rehabilitation Journal, 13(1), 23-32.

Romano, M. D. (1974). Family response to traumatic head injury. Scandinavian Journal of Rehabilitation Medicine, 6, 1-4.

Reinhard, S. C. (1994). Living with mental illness: Effects of professional support and personal control on caregiver burden. Research in Nursing & Health, 17, 79-88.

Rubio, D. M., Berg-Weger, M., & Tebb, S. S. (1999). Assessing the validity and reliability of well-being and stress in family caregivers. Social Work Research, 23(1), 54-64.

Saleeby, D. (1996). The strengths perspective in social work practice: Extensions and cautions. Social Work, 41(3), 296-305.

Sander, A. M., High, W. M., Jr., Hannay, H. J., & Sherer, M. (1997). Predictors of psychological health in caregivers of patients with closed head injury. Brain Injury, 11(4), 235-249.

Schutz, A. (1962). The problem of social reality. The Hague: Martinus Nijhoff.

Semlyen, J. K., Summers, S. J., & Barnes, M. P. (1998). Aspects of caregiver distress after severe head injury. Journal of Neurologic Rehabilitation, 12, 53-60.

Serio, C. D., Kreutzer, J. S., & Witol, A. D. (1997). Family needs after traumatic brain injury: A factor analytic study of the Family Needs Questionnaire. Brain Injury, 11(1), 1-9.

Smerglia, V. L., & Deimling, G. T. (1997). Care-related decision-making satisfaction and caregiver well-being in families caring for older members. The Gerontologist, 37(5), 658-665.

Smith, J. E. (1998). Experiences of caregivers in arranging services for survivors of traumatic brain injury. Unpublished master's thesis, University of Alberta, Edmonton, Alberta, Canada.

Springer, J. A., Farmer, J. E., & Bouman, D. E. (1997). Common misconceptions about traumatic brain injury among family members of rehabilitation patients. Journal of Head Trauma Rehabilitation, 12(3), 41-50.

Stanard, R. P. (1999). The effect of training in a strengths model of case management on client outcomes in a community mental health center. Community Mental Health Journal, 35(2), 169-179.

Stephens, M. A. P., Norris, V. K., Kinney, J. M., Ritchie, S. W., & Grotz, R. C. (1988). Stressful situations in caregiving: Relations between caregiver coping and well-being. Psychology and Aging, 3(2), 208-209.

Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: The development of the experience of caregiving inventory. Social Psychiatry & Psychiatric Epidemiology, 31, 137-148.

Tamm, M. (1999). What does a home mean and when does it cease to be a home? Home as a setting for rehabilitation and care. Disability and Rehabilitation, 21(2), 49-55.

Tebb, S. (1995). An aid to empowerment: A caregiver well-being scale. Health & Social Work, 20(2), 87-92.

United Way of America. (June, 1999). <u>Outcome Measurement Resource Network.</u> Alexandria, VA: Author. Retrieved June 16, 2001, from the World Wide Web: http://national.unitedway.org/outcomes/

Vogenthaler, D. R. (1987). An overview of head injury: Its consequences and rehabilitation. <u>Brain Injury, 1</u>(1), 113-127.

Walker, A. E. (1972). Long-term evaluation of the social and family adjustment to head injuries. <u>Scandinavian Journal of Rehabilitation Medicine, 4,</u> 5-8.

Wallhagen, M. I., & Brod, M. (1997). Perceived control and well-being in Parkinson's disease. <u>Western Journal of Nursing Research, 19</u>(1), 11-31.

Willer, B., Allen, K., Durnan, M., & Ferry, A. (1990). Problems and coping strategies of mothers, siblings and young adult males with traumatic brain injury. <u>Canadian Journal of Rehabilitation, 3</u>(3), 167-173.

Willer, B., Button, J., Rempel, R. (1999). Residential and home-based postacute rehabilitation of individuals with traumatic brain injury: A case control study. <u>Archives of Physical Medicine and Rehabilitation, 80,</u> 399-406.

Willer, B., Flaherty, P., & Coallier, S. (1999, June). <u>Families living with the effects of acquired brain injury.</u> Paper presented at the Third World Congress on Brain Injury, Québec City, PQ.

Wilson, J. (1983). <u>Social Theory.</u> Englewood Cliffs, NJ: Prentice-Hall, Inc.

Wood, R, L., & Yurdakul, L. K. (1997). Change in relationship status following traumatic brain injury. <u>Brain Injury, 11</u>(7), 491-502.

World Health Organization. (n.d.). <u>The concepts of disablement and functioning.</u> Geneva: Author. Retrieved April 29, 2001, from the World Wide Web: http://www.who.int/icidh/brochure/concepts.htm

World Health Organization. (n.d.). <u>The improvements found in ICIDH-2.</u> Geneva: Author. Retrieved April 29, 2001, from the World Wide Web: http://www.who.int/icidh/brochure/improvements

Wuest, J. (1997). Illuminating environmental influences on women's caring. <u>Journal of Advanced Nursing, 26,</u> 49-58.

Zarit, S. H. (1989). Do we need another "stress and caregiving" study? <u>The Gerontologist, 29</u>(2), 147-148.

Appendix A: Letter to Survivor or Legal Guardian

Dear (survivor or legal guardian):

We are doing a study of caregivers providing care to former patients of the Brain Injury Rehabilitation Program. The study is being done by researchers at the University of Alberta. It will look at the qualities of unpaid caregivers and how they arrange care for someone with a brain injury. In this study, a caregiver is someone who provides care or emotional support for someone with traumatic brain injury. The information from this study will help us understand more about caregivers and how to support them in the community.

Our information shows that you are the legal guardian of (patient name) OR Our information shows that you do not have a legal guardian. We would like your permission to contact (your/patient's name's) main caregiver to ask him or her to conduct a telephone survey with us. We would also like your permission to provide the researchers at the University with some information from (your/patient's name's) records. Our staff will provide the researchers with general information about (you/patient's name) and the nature of (your/his/her) injury (such as your/his/her age and how serious your/his/her injury was). No one but our own staff will see your file.

You are not obligated to provide this information. All of the information you do provide will be kept confidential. The results of the caregiver survey and (your/patient's name's) personal information will be combined with information from other people surveyed. No one will know who has participated in the study. Your decision to provide this information will not affect any services (you/patient's name) are/is receiving. We would like to include people in our study who are happy with their experiences at the Brain Injury Rehabilitation Program, as well as those who are not.

One of our staff will be contacting you by telephone in a few days. This person's name is (name). She will answer any questions you have. She will ask you for your permission to pass the information on to the researchers. She will also ask you for the name, address, and telephone number of (your/patient's name's) main caregiver.

If you are concerned about any part of this study you may call me at (phone number). If you would prefer to speak to someone who is not involved in doing this study, you may call Ms. Heather Fox, Patient Advocate at the Alberta Hospital Ponoka at (phone).

Thank you very much for your time.

Yours sincerely,
Mr. Malcolm McKenzie
Program Manager
Brain Injury Rehabilitation Program

Appendix B: Script for Telephone Follow-up with Survivor or Legal Guardian

Hello, may I please speak with (name). My name is (name). I am calling from the Brain Injury Rehabilitation Program in Ponoka. You should have received a letter in the mail describing a study we are doing; did you receive this? (if no: read information letter)

1. Do you have any questions about this study?
2. Do you understand that you have the right to refuse to give permission to use this information? (Yes/No)
3. Do you understand that your decision to participate will not affect any services (you/patient's name) are/is receiving? (Yes/No)
4. Do you understand that all the information you give will be strictly confidential and that no one but the researchers at the University of Alberta will know who has participated in the study? (Yes/No)

Do you give us permission to pass on information from (your/patient's name's) files to the researchers at the University of Alberta? (yes/no)

(if yes): Do you give us permission to contact (your/patient's name's) main caregiver to ask him or her to do a telephone survey with us? (yes/no)

(if no to either of the above): That's fine. Thank you very much for your time. Good bye

(if yes): Thank you. May I have the name, address, and telephone number of (your/patient's name's) caregiver? This is the person who provides the most support to (you/patient's name) by helping (you/him/her) with housekeeping, personal care, rehabilitation or emotional support. This may be may be a family member, friend, or relative, and they must not be paid for providing this support. (record information)

Thank you for your time. Good bye.

Appendix C: Letter to Telephone Survey Participants

Dear (Caregiver),

We are doing a study of caregivers providing care to former patients of the Brain Injury Rehabilitation Program in Ponoka, Alberta. The study is being done by researchers at the University of Alberta. It will look at the qualities of unpaid caregivers and the kinds of care and support they are providing to someone who has survived a brain injury. The information from this study will help us understand more about caregivers and how to support them in the community.

We understand that you are the main caregiver for someone with a brain injury. We would like to conduct a survey with you by telephone to find out what strengths you have as a caregiver, and the kinds of care and support you provide. The survey will ask questions about you, the person you care for, and the people or community services that support you.

The survey is voluntary. Your decision to participate or not to participate will not affect any services you are receiving. Any information you give us is strictly confidential. The information will be kept on a computer file with no names. The Brain Injury Rehabilitation Program will receive a summary of the results from the study. No individuals will be named in the results.

Your participation is very important to us. The information from this survey may help caregivers and brain injury survivors in the future.

An interviewer from the Population Research Laboratory at the University of Alberta will call you in the next few days to ask if you are willing to do the survey. It takes about 30 minutes to complete.

If you have any questions about this study you may call me at (phone). You may also call Ms. Heather Fox, Patient Representative at the Alberta Hospital Ponoka at (phone) if you have any concerns about the study. Thank you for your time.

Sincerely,
Lory Laing
Professor
University of Alberta

Appendix D: Telephone Survey Questionnaire

INTRODUCTION

1.   Hello, my name is _____ and I'm calling (long distance) from the Population Research Laboratory at the University of Alberta. May I please speak with (caregiver's name) ?

        1   Yes (GO TO 2)
        2   No (If not available, don't advance; schedule a callback.)

Hello, Mr./Mrs. _____, my name is _____ and I'm calling from the Population Research Laboratory at the University of Alberta. I'm calling about the caregiver survey that we are doing for the Brain Injury Rehabilitation Program at the Alberta Hospital Ponoka. Did you receive a letter in the mail describing this survey to you?

        1   Yes (GO TO 3)
        2   No (READ INFORMATION LETTER AND GO TO 4)

3.   Did you have time to read this letter?

        1   Yes (GO TO 4)
        2   No   (READ INFORMATION LETTER AND CONTINUE TO 4)

4.   I would like to do the survey with you now if you are willing. It will take about 40 minutes of your time, depending on your answers. Is this a good time to be interviewed?

        If Yes, continue.
        If No, arrange callback and terminate call

5.   Thank you. Before we start, I would like to assure you that your participation is voluntary and that any information you provide will be kept confidential and anonymous. If there is a question you don't want to answer, you can just tell me and we will go on to the next question. You, of course, have the right to terminate the interview at any time.

If you have any questions about the survey, you may contact either one of the researchers on this project: Dr. Lory Laing, Professor at the University of Alberta (phone 780-492-6211) or Heather Lissel, Research Assistant, at the Alberta Centre for Injury Control (phone 780-492-2330).

Only the researchers from the University who are working on this project will see your answers. Responses from all the people will be combined so that no one will know the

answers you have given. Only myself and the project researchers will know that you have participated.

6.   Do I have your permission to begin?

        If Yes, continue
        If No, terminate call and record reason for refusal.

        NOTE TO INTERVIEWER: START TIMING INTERVIEW NOW.

1.   Record sex of respondent

        1   Female
        2   Male

The questions I will be asking you are about the care and support you are providing to your (relation, name). I would like to begin by asking a few questions about him/her.

First of all, I need to confirm that she/he is your (relation).

        01   husband or common-law partner
        02   ex-husband
        03   son
        04   son-in-law
        05   brother
        06   brother-in-law
        07   father
        08   father-in-law
        09   grandfather
        10   uncle
        11   grandson
        12   wife or common-law
                partner
        13   ex-wife
        14   daughter
        15   daughter-in-law
        16   sister
        17   sister-in-law
        18   mother
        19   mother-in-law
        20   grandmother
        21   aunt
        22   granddaughter
        23   boarder

24   friend
        25   hired help
        26   Other (specify): _____
        99   Refused

3.   And is s/he ....

        1   living with you (GO TO 7)
        2   living independently in his/her own home (GO TO 7)
        3   NEITHER (GO TO 4)

4.   Where is s/he living now?

        1   With other family
        2   In a residential or group home [not a long-term care institution]
        3   In long term care institution
        4   In hospital
        5   Passed away (TERMINATE INTERVIEW–GO TO TERM1, SCRIPT A)

5.   How long has s/he lived there?

        1   3 months or less
        2   More than 3 months (TERMINATE INTERVIEW – GO TO TERM 2,
                SCRIPT B)

Do you expect that s/he will move back home with you, or back into his/her own home in
the next 12 months? (PROMPT: your best guess)

        1   Yes
        2   No/DK (TERMINATE INTERVIEW – SEE SCRIPT B)

STOP INTERVIEW – I'm sorry to have bothered you. We are talking with people who
are currently providing care for a brain injury survivor, so I won't need to interview you.
Do you have any questions before I go? Thank you for your time.

NOTE: Automatic disposition code 22 (Deceased)

STOP INTERVIEW – This survey is for people currently caring for someone with brain
injury who lives with them or in their own home. Since (survivor) isn't living with you, I
won't need to interview you. Thank you very much for your time. Do you have any
questions before I go?

NOTE: Automatic disposition code 23 (Not currently living with caregiver, or living on
their own)

In this survey, a caregiver is someone who provides care or support to an adult with a brain injury. Care includes things like bathing, dressing or helping with medication. Support includes things like helping with an emotional problem, helping (him/her) find suitable activities, or doing things together.

How long have you been providing care or support to (survivor)?

_____ years (two digits, round to nearest year)

INTERVIEWER NOTE: < 1 year = 70 + number of months providing care (e.g. 6 months = 76)

DON'T KNOW (after prompt) = 88   REFUSAL = 99

Over the past _____ year/s (months), has being a caregiver to your (relation) become easier in some ways?

    1   Yes
    2   No (GO TO 10)
    0   Refusal (GO TO 10)

In what ways has caregiving become easier? (OPEN-ENDED)

_____

_____

10.   Over the past ___ year/s (months), has being a caregiver to your (relation) become more difficult in some ways?

    1   Yes
    2   No (GO TO 12)
    0   Refusal (GO TO 12)

11.   In what ways has it (caregiving) become more difficult? (OPEN-ENDED)

_____

_____

12. Now I'd like to ask some general questions about you and the people you live with. Not including yourself how many people live with you, including (your relation and) any (other) children?

(INTERVIEWER NOTE: include survivor if survivor is living with caregiver; include children away at school or in joint custody)

Number (2 digits, please): ___ (if zero, GO TO 16)

REFUSAL = 99

13. Starting with the youngest person who lives with you, how old is this person?

_____

INTERVIEWER NOTE: <1 year = 0

REFUSAL = 99

14. And how is this person related to you? (use codes below)

01   husband or common-law partner
02   ex-husband
03   son
04   son-in-law
05   brother
06   brother-in-law
07   father
08   father-in-law
09   grandfather
10   uncle
11   grandson
12   wife or common-law partner
13   ex-wife
14   daughter
15   daughter-in-law
16   sister
17   sister-in-law
18   mother
19   mother-in-law
20   grandmother
21   aunt
22   granddaughter
23   boarder
24   friend
25   hired help

26   Other (specify): _____
99   Refused

(REPEAT WITH Q13 and Q14 FOR REMAINING MEMBERS OF HOUSEHOLD, i.e. For the next youngest person in your household, what is this person's age? And how is this person related to you?)

(IF CAREGIVER HAS CHILDREN UNDER 16 YEARS OF AGE): Do any of your children (under 16 years of age) have physical or emotional needs that require extra care or attention?

Number: _____ (No = 0) NOT APPLICABLE = 9

16.   In which age category do you belong? (READ CATEGORIES)

1   18-24 years
2   25-34 years
3   35-44 years
4   45-54 years
5   55-64 years
6   65-74 years
7   75 years or older
0   Refused

17.   Compared to other people your age, would you say your health is …

1   Excellent
2   Very Good
3   Good
4   Fair
5   Poor
6   Don't Know (VOLUNTEERED)
0   Refused

18.   In the last three months, were you limited in your ability to do the things you wanted to do because of a long-term health problem or disability?

(INTERVIEWER NOTE: long-term refers to a condition that has lasted or is expected to last 6 months or longer.)

1   Yes
2   No
3   Don't Know
0   Refusal

19. Are you currently a caregiver for any other adults besides your (relation)? Care includes help with housework, personal care, emotional support, or arranging for services for someone. These are things that you don't do for pay or as part of a volunteer position. You may include friends or relatives who live with you or elsewhere.

INTERVIEWER NOTE: this includes any children sixteen years of age or older.

Number: _____ (one digit, No = 0) REFUSAL = 9

20. I would like to talk to you now about your (relation) and your role providing care and support for him/her. Since s/he left the Brain Injury Program in Ponoka, has s/he lived in any of the following places for longer than three months?

	Yes	No	D/K	Ref
With other family	1	2	3	0
In his/her own home (not with you)	1	2	3	0
In a long term care facility	1	2	3	0
In hospital	1	2	3	0
Has s/he lived anywhere else that I haven't mentioned Please specify. (OPEN-ENDED)				

_____

21. Over the next 12 months, do you think that your (relation's) living arrangements will probably stay the same as they are now?

1 Yes, will probably stay the same (GO TO 23)
2 No, will probably change
3 Don't know (after prompt) (GO TO 23)
Refusal (GO TO 23)

What kind of living arrangements do you think your (relation) will probably move to?

(DO NOT READ LIST. MARK ONE RESPONSE ONLY.)

1 With other family
2 Into his/her own home
3 Into a long term care institution
4 Into hospital
5 Move into caregiver's home
6 Other living arrangement (specify):_____

Refusal

These next questions are about your (relation's) level of independence. Is your (relation) able to …

	Yes	No	Refusal
Be at home alone	1	2	0
Drive a car without supervision	1	2	0
Look after his/her own personal care such as eating, dressing and bathing	1	2	0
Make decisions about what to do today	1	2	0
Make decisions about the future	1	2	0
Speak well enough to be understood by strangers	1	2	0
Control his/her actions	1	2	0

24.   I am going to read you a list of ways that caregivers may provide care and support to someone with a brain injury.   For each situation, please tell me if you have provided this type of care or support to your (relation) in the last three months.

	Yes	No	Refusal
Helping him/her with eating food	1	2	0
Helping her/him bathe or use the toilet	1	2	0
Helping with dressing, combing hair or brushing teeth	1	2	0
Helping with getting out of bed or a chair, or walking short distances	1	2	0
Helping her/him with medications	1	2	0
Monitoring her/his health	1	2	0
Helping with rehabilitation or re-learning	1	2	0
Communicating with doctors or nurses or other health care providers	1	2	0
Arranging for someone to stay with her/him when you are out	1	2	0
Helping her/him deal with her/his emotions	1	2	0
Looking for services or resources to help him/her	1	2	0

Are there other ways you have supported or cared for (survivor) that I haven't mentioned? Enter one response per window. (OPEN-ENDED)

1. _____

2. _____

25. Thinking about the last three months, about how many hours a week have you spent providing these kinds of care and support? (Prompt: on average)

INTERVIEWER NOTE: (24 hours/day, 7 days/week = 168 hours)

_____ hours (OPEN-ENDED, indicate either per day or per week in the window)

1 Per day
2 Per week

Don't know/No Response

The next question is about services that (survivor) has used in the last three months. In the last three months, has s/he ...

	Yes	No	D/K	Ref
Talked with a psychologist, counsellor or social worker	1	2	3	0
Talked with a family doctor or public health nurse	1	2	3	0
Participated in a support group	1	2	3	0
Received homecare or home nursing	1	2	3	0
Participated in an adult day program	1	2	3	0
Received meals on wheels	1	2	3	0
Participated in a group recreational activity	1	2	3	0
Received job training or vocational services	1	2	3	0
Used specialized transportation services	1	2	3	0

Are there any other services that (survivor) has used in the last three months?

1. _____

2. _____

27. Thinking about yourself now, which of the following activities and services have been a support to you in the last three months?

	Yes	No	NR
Respite services	1	2	0
Talking with a family doctor or public health nurse	1	2	0
Talking with a psychologist, counselor or social worker	1	2	0
Talking with a priest, pastor, or other spiritual leader	1	2	0
Going to church or another place of worship	1	2	0

Participating in a community service club	1 2	0
Exercising	1 2	0
Taking a course	1 2	0
Talking with a close friend or family member	1 2	0
Doing a hobby	1 2	0

Are there other services or activities that
have been a support to you in the last three
months that I haven't mentioned?

1. _____

2. _____

These next questions are about you, and not the person you are providing care and support to.

I am going to read you a list of daily activities like house-cleaning and spending time with friends. On a scale of 1 to 5, please tell me to what extent you think each activity is taken care of in a timely way. "1" means "Never or almost never", and "5" means "Almost always". You do not have to be the one doing the activity. There may be many reasons why it isn't done in a timely way.

(INTERVIEWER NOTE: caregiving responsibilities do not have to be the reason for these needs not being met)

The first activity is buying food. Thinking about the last three months, to what extent do you think this activity has been taken care of in a timely way?

Never/ almost never				Almost always	Don't Know	Refused (Volunteered)
1	2	3	4	5	6	0

28.	buying food	_____
29.	preparing meals	_____
30.	getting the house clean	_____
31.	getting the yard work done	_____
32.	getting home maintenance done	_____
33.	having adequate transportation	_____
34.	purchasing clothing	_____
35.	washing and caring for clothing	_____
36.	relaxing	_____
37.	exercising	_____
38.	enjoying a hobby	_____

39.	starting a new interest or hobby	_____
40.	attending social events	_____
41.	taking time for reflective thinking	_____
42.	having time for inspirational or spiritual interests	_____
43.	noticing the wonderment of things around you	_____
44.	asking for support from your friends or family	_____
45.	getting support from your friends or family	_____
46.	laughing	_____
47.	treating or rewarding yourself	_____
48.	maintaining employment or career	_____
49.	taking time for personal hygiene and appearance	_____
50.	taking time to have fun with family or friends	_____

51.　How often do you feel you had support from others to make sure these activities of daily living were taken care of in a timely way? Would you say you had support…

1	Never or almost never (GO TO 53)
2	Seldom (GO TO 53)
3	Sometimes
4	Often
5	Almost always
6	Don't know (GO TO 53)
0	Refusal (GO TO 53)

52.　Who do you feel has been the most support to you making sure these activities of daily living are taken care of in a timely way? (OPEN-ENDED)

Do not record proper names, instead record relationship of person to caregiver (e.g. my sister-in-law).

Survivor=77
Don't know = 88
Refusal = 99

_____

Next I am going to read you a list of basic needs such as getting enough sleep and eating a well balanced diet. On a scale of 1 to 5, please tell me to what extent you think each activity is taken care of in a timely way. "1" means "Never or almost never", and "5" means "Almost always".

(INTERVIEWER NOTE: caregiving responsibilities do not have to be the reason for these needs not being met)

The first need is having enough money. Thinking about the last three months, to what extent do you think this need has been taken care of in a timely way?

Never/ almost never				Almost always	Don't Know	Refused (Volunteered)
1	2	3	4	5	6	0

53.	having enough money	_____
54.	eating a well balanced diet	_____
55.	getting enough sleep	_____
56.	attending to your medical and dental needs	_____
57.	having time for recreation	_____
58.	feeling loved	_____
59.	expressing love	_____
60.	expressing laughter and joy	_____
61.	expressing sadness	_____
62.	enjoying sexual intimacy	_____
63.	learning new skills	_____
64.	feeling worthwhile	_____
65.	feeling appreciated by others	_____
66.	feeling good about family	_____
67.	feeling good about yourself	_____
68.	feeling secure about the future	_____
69.	having close friendships	_____
70.	having a home	_____
71.	making plans about the future	_____
72.	having people who think highly of you	_____
73.	having meaning in your life	_____
74.	expressing anger	_____

75. How often do you feel you had support from others to make sure your basic needs were met? Would you say you had support...

1	Never or almost never (GO T0 77)
2	Seldom (GO TO 77)
3	Sometimes
4	Often
5	Almost always
6	Don't know (GO TO 77)
0	Refusal (GO TO 77)

76. Who do you feel has been the greatest support to you in making sure your basic needs have been met?

Do not record proper names, instead record relationship of person to caregiver (e.g. my sister-in-law).

Survivor=77
Don't know = 88
Refusal = 99

_____

77. I would like to ask some questions about your experiences as a caregiver. What would make your life as a caregiver easier? (OPEN-ENDED)

Don't know = 88 (after prompt)
Refusal = 99

_____
_____

78. Describe two or three things about yourself that you feel have helped you to be a caregiver. (OPEN-ENDED)

Don't know = 88 (after prompt)
Refusal = 99

_____
_____

This final set of questions are about yourself and the community where you live. These questions will give us a better picture of the people who took part in the study and help us to compare the situations of the caregivers we are surveying.

79. What is the highest level of education you have attended or completed?
(DO NOT READ LIST)

1   No schooling
2   Some Elementary
3   Completed Elementary
4   Some Secondary
5   Completed Secondary

6   Some college, technical, or nurse's training
        7   Some University
        8   Completed University
        9   Other education or training (please specify)_____
        0   Refusal

80.   What is the highest level of education your (relation) has attended or completed?
(DO NOT READ LIST)

        1   No schooling
        2   Some Elementary
        3   Completed Elementary
        4   Some Secondary
        5   Completed Secondary
        6   Some college, technical, or nurse's training
        7   Some University
        8   Completed University
        9   Other education or training (please specify)_____
        0   Refusal

Are you employed?

        1   Yes, full-time (GO TO 83)
        2   Yes, part-time (GO TO 83)
        3   On leave [e.g. pregnancy, medical, compassionate] (GO TO 83)
        4   Other: _____ (GO TO 83)
        5   No
        0   Refusal (GO TO 83)

82.   Are you ... (READ. Select best response.)

        1   Unemployed
        2   Retired, or
        3   A student
        4   Other (please specify): _____ (e.g. on disability
                leave)
        5   Homemaker
        0   Refusal

83.   Do you do volunteer work in the community?

        1   Yes
        2   No
        0   Refusal

84.   How far is your home from the nearest city? (OPEN-ENDED)

_____ (three digits)

INTERVIEWER NOTE: LIVES IN CITY = 000
Refusal = 999

Be sure to write in kms or miles!

miles   1
kilometres   2

85.   Have you had to move to another community to care for or receive services for your (relation)?

    1   Yes
    2   No
    0   Refusal

86.   Do you own or rent your home?

    1   Own
    2   Rent
    3   Other (please specify) _____
    0   Refusal

87.   Which of the following categories best reflects your total household income last year, before taxes. Was it …

    1   less than $20,000
    2   between $20,000 and $40,000
    3   more than $40,000
    0   refusal

88.   What is your marital status? (PROBE IF RESPONDENT SAYS "SINGLE")

    1   Married or common-law
    2   Divorced
    3   Separated
    4   Single, never married
    5   Widowed
    0   Refusal

89.   Is English your first language?

1   Yes
2   No
0   Refusal

Do you have any other comments you would like to make about your role as a caregiver, or comments you would like to make about this survey? (OPEN-ENDED)

None = 00
Refusal = 99

_____

_____

_____

We would like to learn more about your skills and how you manage your responsibilities as a caregiver. In the summer we will be completing a second part to this study. This part of the study will involve personal interviews with caregivers like yourself who have completed this survey. We would like to contact you in the summer regarding this part of the study. We will only contact you if you are willing to participate further. You aren't obligated to participate and you can always change your mind in the future.

91.   Are you willing to be contacted again for a personal interview in a few months?

1   Yes
2   No (GO TO TERM)

92.   In case we are unable to locate you at this telephone number when we call again, could you give us another telephone number of a family member or friend who would know how we could get in touch with you?

Contact person's name: _____

Phone number: _____

Refused/Don't know = 999-999-9999

We've reached the end of our questions and I'd like to thank you very much for taking the time to do this interview.

This section to be completed by Interviewer: results to be aggregated separately from main interview.

93.   How would you rate the respondent's comprehension of the questions?

1　　　Excellent
　　　　2　　　Very Good
　　　　3　　　Good
　　　　4　　　Fair
　　　　5　　　Poor

94.　　How would you rate the respondent's interest in the survey?

　　　　1　　　Excellent
　　　　2　　　Very Good
　　　　3　　　Good
　　　　4　　　Fair
　　　　5　　　Poor

95.　　How would you rate the respondent's openness, frankness?

　　　　1　　　Excellent
　　　　2　　　Very Good
　　　　3　　　Good
　　　　4　　　Fair
　　　　5　　　Poor

96.　　How would you rate the overall quality of the interview?

　　　　1　　　Excellent
　　　　2　　　Very Good
　　　　3　　　Good
　　　　4　　　Fair
　　　　5　　　Poor

Do you have any other comments about the interview? (Thumbnail sketch)

　　　　None = 00

1.　　Please record the length of the interview in minutes. _____

2.　　PLEASE GO THROUGH THE QUESTIONNAIRE AGAIN FOR YOUR FINAL EDIT BEFORE RECORDING IT AS A "COMPLETED INTERVIEW".

Appendix E: Key Findings From the Telephone Survey

Caregiver characteristics

The 28 caregivers who participated in the telephone survey ranged in age from approximately 35 to 74 years of age. The highest percentage of caregivers (42.9%; n=21) were in the 55 - 64 year age category. Most (82.1%; n=23) were females, and mothers of a brain injured child (53.6%; n=15). Another seven (25.0%) were wives whose husbands had a brain injury, and one was a female providing care for a girlfriend with a brain injury. Of the six male respondents, two were fathers of brain injured children, one was a husband, one a brother, and one a son providing care for his father who was living with a brain injury.

The typical household structure was a husband and wife couple living with an adult child with brain injury (35.7%; n=10). 85.7% (n=24) of caregivers were married or living common-law, one (3.6%) was divorced, and three (10.7%) were widowed. Given the average age of caregivers, few (10.7%; n=3) had children under 18 years of age. Three (10.7%) were living with adult children (18 years or older).

The care recipient was living with the caregiver in 71.4% of cases (n=20). Seven (25.0%) care recipients were living independently and one (3.6%) had moved to a residential group home less than three months earlier.

The length of time respondents had been providing care to the survivor ranged between one year and ten years. A majority of respondents had been providing care and support to the survivor for 6 or more years (42.9% n=12). Another 11 had been caregivers for 3 -5 (39.3%) years, and 5 (17.9%) for 1 - 2 years.

Taking into consideration the limitations of questions regarding caregiving arrangement, it appeared that the caregiver/care recipient arrangement was fairly stable over time. Only two care recipients had lived with other family for more than three months and none had lived in a long term care facility for more than three months and returned to live with the

caregiver. Only two respondents indicated that they expected a change in the care recipient's residence in the next 12 months - one anticipated the survivor to move into a group home, and another expected a move into a seniors complex. Six (21.4%) had to move to another community to care for or receive services for the survivor.

Just over a third (35.7%; n=10) of respondents were working full-time and another 5 (17.9%) were working part-time. Of the remaining 13, six were full-time homemakers & caregivers - including one who was "unemployed until survivor is able to care for herself", and one who took a medical discharge because of stress at work and home.

Similar numbers of respondents had incomplete secondary education (32.1 %; n=9) complete secondary education (21.4%; n=6), and incomplete college or technical training (28.6%; n=8). Four (14.3%) had some university education and one indicated "other" (3.6%). English was the first language for 24 (85.7%) caregivers.

Household income was roughly evenly distributed across income categories for the 26 individuals who responded to this question. Seven (26.9%) reported an income of less than $20,000 per year before taxes; nine (34.9%) reported an income between $20,000 and $40,000 per year, and ten (38.5%) reported an income over $40,000 per year.

The caregiving experience

The caregiving experience for each of the 28 respondents is described by questions about the level of the care recipient's function and services utilized, the number and type of caregiving tasks performed, and the number of hours per week spent caregiving.

To determine care recipients' level of function, caregivers were asked to respond whether or not the recipient could perform seven separate tasks ranging from bathing and eating to driving a car and making decisions about the future. A rough determination of level of function can be made by looking at the overall number of tasks that can be performed, while detail about specific capacities is available by looking at individual items in the list.

A majority of respondents indicated that the care recipient was capable of performing 5 or more of the tasks in the list (53.6%; n=15). The most frequently cited difficulties were with driving a car without supervision (75% couldn't; n=21), making decisions about the future (71.4% couldn't; n=20) and making decisions about what to do today (42.9% couldn't; n=12). These represent significant limitations to establishing independence and may have a significant impact on caregiver well-being, as family and friends might be depended upon more than paid caregivers to provide support in these areas, especially decision-making. As well, interviewers noted several instances where respondents responded affirmatively about the survivor's abilities, but qualified this by stating that "s/he needs to be reminded" or "s/he can do it if I tell/show her/him how".

Caregivers were asked to indicate which in a list of nine services the survivor had used in the last three months. In spite of the large number of survivors apparently needing emotional support, only 4 (14.3%) had talked with a psychologist, counselor or social worker. Eighteen (64.3%) had talked to a family doctor or public health nurse, indicating the importance of arming these health professionals with adequate information to identify and treat the types of physical and emotional problems commonly experienced by brain injury survivors. Only 4 (14.3%) had participated in a support group in the last three months and 8 (28.6%) had participated in a group recreational activity, supporting caregivers' concerns about social isolation which arose throughout the survey. Six (21.4%) used some form of specialized transportation, in spite of the fact that fully 100% of survivors were unable to drive alone. These findings point to a potentially high reliance on caregivers to maintain the emotional well-being, social involvement, personal growth and independence of brain injury survivors.

Caregivers' duties reported in the survey were generally quite extensive and varied. Thirteen (46.4%) caregivers stated 6 or more separate tasks that they did for the care recipient. These included things such as monitoring the survivor's health (71.4%; n=20), helping with rehabilitation or relearning (67.9%; n=19), communicating with health care providers (67.9%; n=19), helping with medication (53.6%; n=15), looking for services or

resources to help survivor (50.0%; n=14), and arranging care for survivor when caregiver goes out (39.3%; n=11) . Fully 100% of caregivers indicated that they provided emotional support to the care recipient. When asked if there were other tasks performed, several caregivers mentioned arranging social activities, preparing meals/ensuring survivor has food or meals, and looking after finances.

Based on the activities that caregivers performed, they were asked to calculate their average number of caregiving hours per week. While the hours of week providing care were difficult for many caregivers to assess, their responses nonetheless showed a great variation in the degree of caregiving responsibility. Half (50.0%; n=14) of caregivers responded that they provided 20 hours or less care per week. Another 32.3% (n=9) averaged their hours to be somewhere between 21 and 35 hours per week, with the remaining 17.9% (n=5) estimating that they spent anywhere from 77 to 168 hours per week (or 24 hours per day) providing care.

Caregiver Well-being

Well-being is being viewed in this study as both an outcome of objective stressors and as a protective factor in managing stressors in one's life. How well-being functions in both these senses is to be studied in greater depth in the personal interviews with caregivers. The telephone survey collected information to guage the overall well-being of caregivers using open-ended questions about how caregiving had become easier or more difficult, self-rated health status, activities that were a support to the caregiver, and scores from the Caregiver Well-being Scale (Tebb, 1995).

Overall, caregivers rated their health slightly low in comparison to the health of other people their age. Fifteen (53.6%) rated their health as good or fair. Another 13 rated their health as very good or excellent (46.4%). None rated their health as poor. Eight (28.6%) reported that they had experienced limitations in their activities due to a long term health problem.

Near the beginning of the survey, respondents were asked whether they felt caregiving had become easier in the years since they first started providing care to the survivor. Twenty-four (85.7%) indicated that it had, and described several ways in which it had become easier. Their responses were analysed thematically into several categories which reflected both changes that had taken place in the caregiver to enable them to deal more effectively with their role, and changes in the care recipient that either made the task of caregiving easier, or more rewarding. Caregivers were also asked whether caregiving had become more difficult in some ways. Slightly fewer (64.3%; n=18) indicated that it had, and indicated ways in which their role had become more difficult. Responses reflected caregivers' personal issues and issues with the survivor. Personal issues included comments reflecting difficult emotional issues ("the sorrow is unbearable"), problems dealing with a lack of understanding from others ("I have to educate myself constantly on legal issues to protect him"), that the problems were simply relentless in nature and therefore getting harder to deal with ("it never ends"), and that the caregiver's personal resources were decreasing ("I'm getting more tired and more stressed"). Some respondents mentioned having conflicts with the survivor over decision-making and what the survivor should or shouldn't do (e.g. driving, smoking). Many caregivers were finding things more difficult as a result of the survivor's continuing social isolation, frustration with not getting better, or other varied behavioural and emotional problems.

Overall, caregivers showed great consistency in the type of activities they found to be a support to them in their role. Twenty-seven (96.4%) found support in talking with close friends or family members in the last three months. Twenty-one (75.0%) found doing a hobby to be supportive; 50.0% (n=14) excercising; and 46.4% (n=13) going to church or some other place of worship.

Caregiver well-being was examined extensively by means of the Caregiver Well-being Scale (Tebb, 1995). This scale consists of two sub-scales, one with 23 questions measuring the degree to which respondents felt that activities of daily living such as buying food and attending social events were met in a timely fashion, and one with 22 questions

measuring the degree to which respondents felt that their basic needs such as having time to laugh and having meaning in their life were met in a timely fashion. Each of the 45 questions was scored on a 5-point Likert scale where 1 indicated that the need is never or almost never met, and 5 meant it is almost always met in a timely way. For the purposes of selecting individuals to contact regarding participation in the personal interviews, scores for each of the questions will be summed to provide a total well-being measure that can be used to compare degree of well-being between the participants. On their own, the individual questions provide a valuable portrait of the caregiving experience.

Within the sub-scale for Activities of Living, the three items most commonly rated as never or almost never being met in a timely way were: starting a new hobby or interest (82.1%; n=23); asking for support from friends or family (71.4%; n=20); and attending social events (64.3%; n=18). The overall proportion of items in the Basic Needs sub-scale that were stated as never or almost never being met in a timely fashion was lower than for the Activities of Living. Here the three most frequently unmet needs were: learning new skills (60.7%; n=17); enjoying sexual intimacy (50.0%; n=14); and having time for recreation (39.3%; 11). In addition, slightly more caregivers felt that they had often or always had support from others to help meet their basic needs (53.6%; n=15) than they did in fulfilling activities of living (42.9%; n=12).

The interview concluded with two questions aimed at gaining insight into the strengths caregivers felt they had, and the resources that would make their life as a caregiver easier. Respondents were asked to name two or three things about themselves that helped them to be a caregiver. The most frequent responses spoke to the caregiver's personal characteristics or outlook on life: courageous, stubborn, patient, strong willed, optimistic, and having a sense of humour were frequent mentions. Many caregivers also responded with statements that reflected a sense of meaning in, or satisfaction with, their caregiving role; "If you love someone, what are the limits?" "I want to do what I can for my son," "I understand what he's going through," "I feel proud I was able to do it," and "we (caregiver and survivor) have a good relationship" were some of the many responses that

reflected this aspect of caregivers' personal character. Other frequent mentions included those that spoke of a special ability to provide care gained through past work or personal experience, learning as much as possible about brain injury, and believing in God or having strong spiritual beliefs.

With respect to the supports that would make their life easier caregivers' responses reflected the need for supports for both themselves and the survivor. Caregivers said that better supports to help the survivor deal with psychological and emotional problems would make their life easier. One caregiver wished that survivor could learn to have fun and enjoy himself. Companionship and greater social involvement for the survivor was mentioned by many caregivers. Several mentioned frustration with survivors who refused to participate in special programs or seek help. Supports that caregivers would like for themselves included a break from the mental strain and responsibility ("a break to forget they exist for a couple of months"), supports so they could have more personal time ("an opportunity to get out for an odd evening"), help with providing care ("someone to share the job"), more money, specialized equipment and home alterations, more time to spend doing things or going out visiting or for meals with survivor, better health, and more understanding from others about the demands of caregiving.

Overall the information gathered in the telephone survey illustrates a complex web of personal and social factors that influence the ability of individuals to be long-term caregivers to someone with a brain injury. Information from the open-ended questions in particular, leads to questions about how caregivers are able to achieve satisfaction in their role and maintain personal well-being in spite of immense strain.

Appendix F: Information Sheet for Face-to-face Interview Participants

Dear Caregiver,

Thank you for sharing your experiences as a caregiver with us in the telephone survey you completed in May. Already we are learning more about what it is like to provide care and support to someone with a serious brain injury.

This study is being done by researchers at the University of Alberta, for the Brain Injury Rehabilitation Program in Ponoka. By talking with you one on one, we hope to learn more about your strengths and how you have been able to deal with the challenges of being a caregiver. This information will help the Brain Injury Program find ways to support caregivers, and may help future caregivers as well.

The interview will take 1 to 1½ hours to complete. It will be tape recorded so that no information is missed. The tapes and my notes will be kept in a secure place. Only I and my supervisor at the University of Alberta (Dr. Lory Laing) will be able to access them.

The information you provide will be kept completely confidential, and no one will know you have participated. Your responses will be combined with the responses of other people participating in this study. The Brain Injury Rehabilitation Program will receive a summary of the study results and will not know what you have said.

Your participation is completely voluntary. Your decision to participate will not affect any services you are receiving. You do not have to answer all the questions and you may stop the interview at any time.

If you would like more information about this study, please call any of the people listed below.

Dr. Lory Laing   Ms. Heather Fox
Professor   Patient Care Advocate
Department of Public Health Sciences   Brain Injury Rehabilitation Program
University of Alberta   Ponoka
(phone)   (phone)

Your contribution is very important. Thank you very much for your time!

Appendix G: Consent Form for Face-to-face Interviews

Project Name: Factors Influencing Caregiving Arrangements

Principal Researcher:	Dr. Lory Laing Professor, Department of Public Health Sciences, University of Alberta Phone: 780-492-6211
Co-Researcher:	Dr. Peter Wass Neuropsychologist, Brain Injury Rehabilitation Program, Alberta Hospital Ponoka Phone: 403-783-7779
Research Assistant/ Interviewer:	Heather Lissel Student, Department of Public Health Sciences, University of Alberta

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Do you understand that you have been asked to be in a research study?   Yes   No

Have you received and read the information letter describing this project?   Yes   No

Do you understand that you can refuse to participate or withdraw from   Yes   No
the interview at any time?

Have you had an opportunity to ask questions and discuss this study?   Yes   No

Do you understand that you are free to refuse to participate or withdraw from   Yes   No
the study at any time?

Has the confidentiality of this study been explained to you? Do you understand   Yes   No
who will have access to the information you provide?

I agree to take part in this study.

_____   _____   _____
Participant's signature   Date   Witness

_____   _____
Printed Name   Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily
agrees to participate.

_____   _____
Signature of Investigator or Designee   Date

Appendix H: Guiding Questions for the Face-to-face Interview

1.   Tell me how you came to be a caregiver for _____?
          What was it like when s/he came home?
          How did your life change?
          How did things change for the rest of your family?

2.a.   Thinking about your life over the last x years, what is the best thing that's happened to you? It may be something related to your role as a caregiver, or it may not.
          When have you felt best or happiest?

2.b.   Why do you say that was the best thing that happened / that was the happiest time for you?

3.a.   Thinking about that same period of time, when did you face your most difficult challenge? Again, it might be something related to your role as a caregiver, or it may not.

3.b.   How were you able to get past that?
          What did you do or someone else do to help you get through that?

4.   What advice would you have for other people who are just starting to be caregivers for someone with a brain injury?